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ABSTRACT

The ten 1998 issues of the newsletter of TASH comprise this document. An issue typically contains news items, a column by the organization's executive director, reports from special interest groups, legislative testimony, conference information, and several major articles, such as the following: "A Q&A on IDEA 97 with Tom Gilhool"; "Positive Behavior Supports and IDEA"; "Highlights of the Discipline Provisions of the Individuals with Disabilities Education Act Amendments of 1997"; "1997 TASH Conference Keynote Address" (Reed Martin); "Institution Closures Continue at an Average of More than 12 per Year" (K. Charlie Lakin and others); "Fighting To Keep 'Em In" (Josie Byzek); "The Deinstitutionalization of America" (James W. Conroy); "Power Sharing between People with Substantial Disabilities and Their Assistants" (John O'Brien and Connie Lyle O'Brien); "Teaching Students To Play" (Linda A. Heyne); "Inclusive Recreation: A Parents' Guide to Quality" (Stuart J. Schleien and John E. Rynders); "It's Summer Time! Let's Go to Camp" (Cynthia Burkhour); "Recreation-Human Services Partnerships: The Rural Recreation Integration Project" (Lynn Anderson and others); "Future Planning for Your Child Takes More than a Will"; "Current Trends in Providing Support for Families of Adults with Mental Retardation" (Tamar Heller); "Securing Self-Determination: Building the Agenda in Canada" (Michael Bach); "Wanted: People with Disabilities Involved in International Development" (Susan Sygall); "Girls and Women with Disabilities: A Global Overview" (Nora Groce); "Native American Communities--A More Inclusive Society?" (Ladonia Fowler); "My Experiences with the Criminal Justice System" (Perry Whittico wity Bonnie Shoultz); "Individuals with Significant Disabilities Who Are Victims of Crime" (James K. McAfee); "Should the Death Penalty Apply to Persons with Cognitive Disabilities: The States Must Decide" (Barbara E. Ransom and Dawn Sutton); "Unleash the Power" (Joyce Lipman); "Internet Resources Concerning People with Developmental Disabilities" (Rachael Zubal and Steve Drake); "Escaping from the Label Trap" (Michael W. Smull); "Changing the News about Disability: Why We Need To and How To Do It" (Mary

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Johnson); "Radical Heart, Moderate Mind: A Perspective on Inclusion" (Peter V. Paul); and "What's Wrong with the Feds?" (Mark A. Mlawer). (DB)

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TASH NEWSLETTER

Volume 23/24
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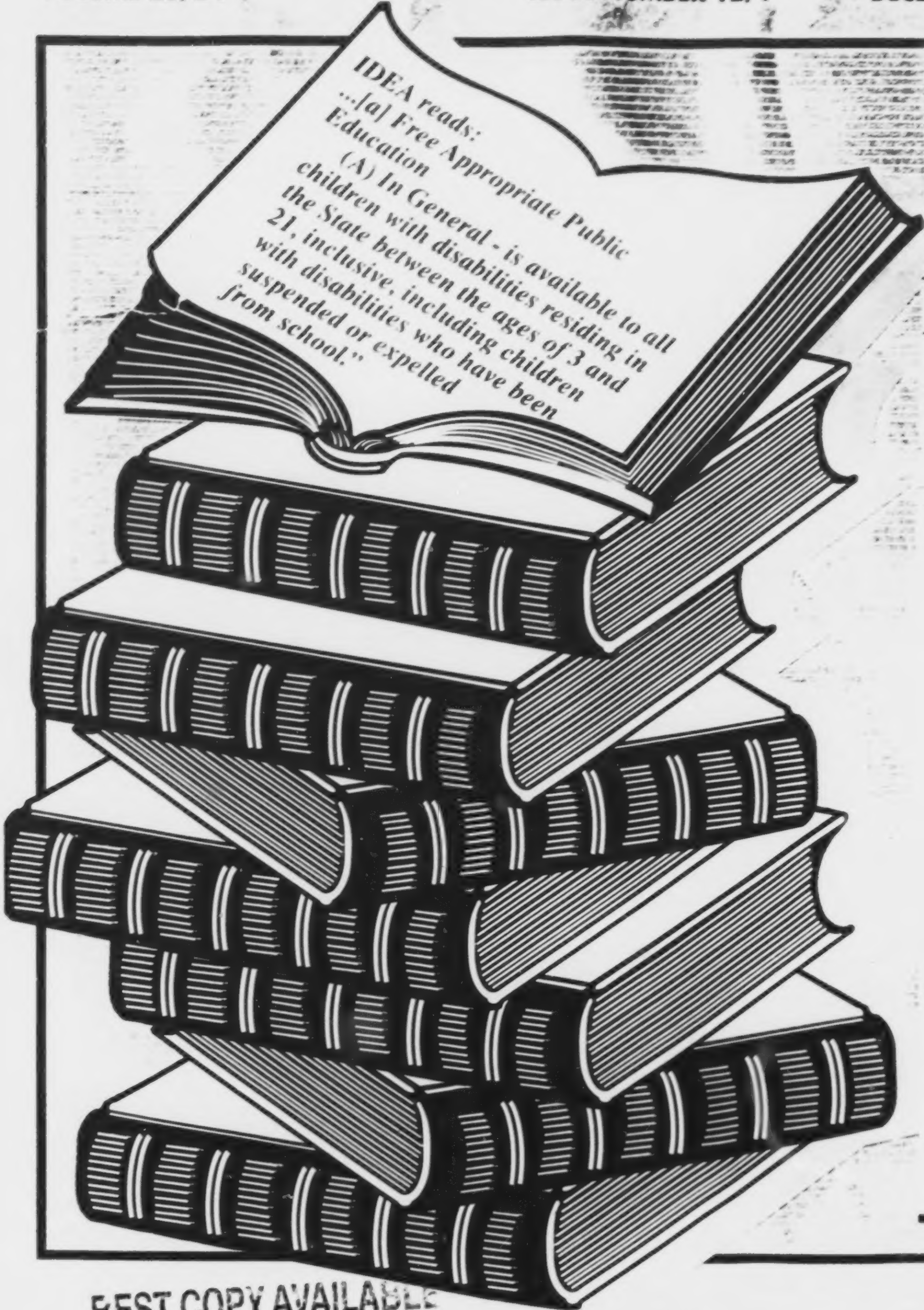
TASH Newsletter

VOLUME 23/24 ISSUE NUMBER 12/1 DECEMBER 1997/JANUARY 1998



IDEA reads:
...[a] Free Appropriate Public Education
(A) In General - is available to all children with disabilities residing in the State between the ages of 3 and 21, inclusive, including children with disabilities who have been suspended or expelled from school."

IDEA '97

In this issue:
- The Impact of Grassroots Advocacy
- Timeline for Implementation
- Discipline, Positive Behavior Supports, and Suspensions
- Discretionary Programs
- Part C: Infants and Toddlers
- State Advisory Panels
- Evaluations, Eligibility, IEPs and Placements
- and more!

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NEWS FROM COLORADO:

Colorado TASH currently is focusing on two major issues: inclusive education and community connections. To that end, Colorado TASH will be co-sponsoring with Colorado PEAK Parent Center the Colorado Inclusion Conference February 19-21, 1998.

For more information on the Colorado Inclusion Conference, contact Peak Parent Center at (719) 531-9400.

TASH CHAPTER
News & Views

Other activities of Colorado TASH include lending support to other organizations' efforts, underwriting pilot projects, providing mini-grants, and recruiting and supporting its members through information and referral.

Connie Christoff is Colorado TASH's president; Robert B. Ruggow, is the treasurer; and Elizabeth Soper Hepp is the Membership Chairperson. Other board members of Colorado TASH are Michael Hoover, Rick Keeton, and Joan Rademacher.

TEXAS TASH

Announces its upcoming state meeting on February 6-7, 1998 in August Hall at Sam Houston State University in Huntsville, Texas.

Registration is scheduled for 4 to 5 PM on Friday, February 6, followed by the welcome and plenary session by Dr. Mike Brady, former President of the Texas Chapter of TASH.

A reception will follow at the home of Sharon Lynch, current President of Texas TASH – all are cordially invited to attend.

Saturday, February 7 will include a keynote address by Mike Brady on "The Stereotypic Behavior of Special Educators." Roundtable discussions on these topics will follow: Legal Issues; Involving Families in the Assessment Process; Non-aversive Behavioral Interventions; Improving Transition Planning; and Teacher-Paraeducator Partnerships.

For more information on the meeting, contact Mary Fitzgerald at 281-583-2285 or Sharon Lynch at 409-294-1122, or send an e-mail to: edu_sal@shsu.edu

COMING SOON: Texas TASH Webpage!!
Watch for details!

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105 or e-mail: info@tash.org

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

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Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

BY MARCIE ROTH

Despite permanent authorization of the Individuals with Disabilities Education Act of 1975 (IDEA), the 105th Congress took it upon itself to rewrite the law that ensures a free and appropriate public education for all children. As Congress moved toward passage of their new law, many families and advocates from across the country stood together and, in a unified voice, said "IDEA is a good law. Leave IDEA alone! Adequately fund it and then monitor and enforce it. Don't change it - make it work!"

The battle was waged on a number of fronts. Despite opposition from numerous grassroots advocacy and parent organizations, many others indicated willingness to compromise in the shadow of what was described by some to be "political reality". Parents and other stakeholders from across the country called on insiders to step aside and allow them to speak for themselves. There was consensus from around the country that political reality could be defined by the grassroots if the insiders would allow the voices outside the Beltway to be heard over the din of Beltway politics.

Despite the best efforts of many, the new law was passed and on June 4th, 1997 the Individuals with Disabilities Education Act of 1997 (IDEA '97) was signed into law.

This edition of the TASH *Newsletter* focuses on various aspects of the Individuals with Disabilities Education Act of 1997 (IDEA '97). Unlike most editions of the *Newsletter*, this one came together very slowly, over a period of six months. It was not intended to be among the first pieces off the presses, but a careful and responsible compilation of some of the most useful information available. There is already quite a bit of information in print, and plenty of misinterpretation as well. This is not

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WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about conference registration or exhibiting call:** Rose Holsey, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
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- **Don't forget to visit TASH's web site at http://www.tash.org**

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surprising. In fact, one of the arguments for leaving IDEA alone was to avoid the inevitable period of interpreting, reinterpreting, and challenging the interpretations of others. Sadly, after 22 years of failed efforts to get the law adequately enforced, all stakeholders have diverted efforts away from a focus on educating the students to one of understanding the new law. Putting the changes into practice will require significant additional efforts. Many are also concerned that the inevitable legal challenges are bound to delay and confound the delivery of educational services even further.

Inside this edition of the *Newsletter* you'll find:

- A candid Q & A with Tom Gilhool (page 5). This article will bring you up to speed about some of the most notable elements of IDEA '97, while describing the winding path that led to the passage of the new law. This piece effectively captures the powerful impact of grassroots advocacy.

- Remember Part H? The portion of the law that set out the requirements for educational services for Infants and Toddlers with Disabilities? It's been renamed Part C and with the invaluable assistance of the National Information Center for Children and Youth with Disabilities, we've included a brief list of the notable changes beginning on page 13.

- Information from the U.S. Department of Education, Office of Special Education Programs (OSEP) explaining the requirement that State Advisory Panels include representation from a majority of individuals with disabilities and parents of children with disabilities (page 15).

- An excerpt from an article written by Rud Turnbull of the Beach Center at the University of Kansas that highlights the significant new safeguards for students and the rights of parents to participate in educational decision making (page 19).

If you wonder how Part H was able to slip so easily into the C position, it is because the previous layout of the Discretionary Programs (the elements that really make the law work) have been condensed from 14 separate authorities to a tidy seven. They have been given the Part D position and retitled "National Activities to Improve Education of Children with Disabilities."

Did you think that the law changed the moment the President's ink dried back on June 4th? Well, it did in some areas, and hasn't yet in others. We've included a Timeline for Implementation (page 11) to help our readers keep track. Presumably, the parts that are not yet effective are still being implemented in good faith, to the best of the ability of every educational entity.

The biggest battles and the hardest moments for all during the past three years were due to the challenging issues of discipline and school safety. Somewhere along the way, children with disabilities, classroom disruption and school safety came to be considered by some as parts of the same discussion. Despite the lack of any evidence that children with disabilities are a demonstrable factor in the problems with disruption and safety in our schools, the disciplining of students with disabilities was a persistent theme. We have included a memorandum and a letter that deal with discipline.

The memo is from Judy Heumann, Assistant Secretary of the US Department of Education, Office of Special Education and Rehabilitative Services (OSERS) and Tom Hehir, Director of the US Office of Special Education Programs (OSEP) (page 28). While this "policy guidance letter" no longer carries the force of law (an IDEA '97 change), we are disappointed with the Department of Education's attempt to interpret the straightforward language of the law. It is also disappointing that the very first communication from them after passage of IDEA '97 is entitled "Initial Guidance Regarding REMOVAL [emphasis added] of Children with Disabilities from their Current Placement."

The new law says, most notably, that a free and appropriate public education must be provided, and access to the general curriculum assured. Sadly, this first interpretation attempts to soften this requirement.

We've followed this document with a response letter from a number of the top legal experts from across the country (page 30). Their response clarifies expectations and delivers a reminder to all that the road to success in our schools will be paved with adequate support for promising educational practices, including an improved system of personnel development and utilization of positive behavioral supports.

The article on discipline, "Highlights of the Discipline Provisions of the Individuals with Disabilities Education Act of 1997," (page 24) comes from the Center for Law and Education and is "hot off the press." It is the article that gives parents, advocates and educators the facts on discipline as they are written in the new law.

The changes in the law require the writing of new regulations. Draft regulations (the "rules") were published on October 22, 1997 and after a 90-day period of public comment, final regulations will be issued, probably sometime next summer. Then begins the next chapter in the process of educating the 5.8 million students with disabilities in the United States. Information on where to obtain a copy of the draft regulations, and who to contact if you are interested in commenting on the proposed regulations, can be found on page 23.

We hope you find this edition of the TASH *Newsletter* to be useful. Now is the time to get smart about the new law. Our work has only just begun. Contact Marcie Roth, TASH's Director of Governmental Affairs and Public Policy at x104 if you have comments or questions pertaining to any of the information contained in this *Newsletter*.

A Q&A on IDEA '97 with Tom Gilhool

TASH gratefully acknowledges the assistance and support of the Autism National Committee in allowing us to reprint substantial portions of this exclusive interview. To obtain copies of the full article, contact the Autism National Committee at 610-649-9139.

■ ■ ■ ■

Thomas K. Gilhool is well known as the mastermind of the PARC Consent Decree, the landmark federal court decision which granted Pennsylvania children with mental retardation the right to public education and laid the foundation on which our first national bill, PL 94-142, was subsequently based. Mr. Gilhool's careful wordsmithing was vital in shaping the language of that national legislation back in 1975. In 1996-97, he was back in Washington to help prevent the threatened erosion of our children's education rights and, wherever possible, to strengthen the language of the Individuals with Disabilities Education Act (IDEA).

■ ■ ■ ■

The following is a candid question and answer session with Tom Gilhool. This article will bring you up to speed about some of the most notable elements of IDEA '97, while describing the winding path that led to the passage of the new law. This piece effectively captures the powerful impact of grassroots advocacy.

Question: Now that the IDEA has finally been reauthorized, we're hearing varied interpretations of what the changes in this law will mean for our children. Some are calling it a greatly improved law, while others are saying that our rights have been eroded. What changes have actually occurred, and what impact are they likely to have?

Tom Gilhool: There is some truth in every one of the diverse characterizations of the new IDEA, which contains a strong side as well as some potential threats.

On the strong side, the Act itself and the Committee Reports which accompany it make very clear the continuing and strengthened commitment to the *integration imperative*. In this regard, every school district must spare no effort to secure the effective and appropriate education of every child in the regular or general education classroom. It is also worth noting that the reports of both the House Committee and Senate Committee are almost verbatim the same, giving them a special joint weight.

Also on the strong side, this Act emphasizes *educational results*, equating successful education with effective education. In the markup and in the Committee Reports themselves you see frequently the chairs of the House and Senate Committees, as well as the major sponsors of the Act, saying that the primary purpose of all these amendments is to go *beyond mere access* to the schools and secure for every child an education that actually yields successful educational results.

To secure real educational results, there are several important new provisions and a renewed emphasis on several original, long-standing provisions. Chief among the newly emphasized provisions is the requirement that all school districts must disseminate among all educators (regular and special), supporting personnel, and administrators information on promising educational practices — systems of teaching and learning that have a record of success — and indeed must *adopt* these practices. This requirement of the Act is preserved in Section 612(a)(14), and by the creation of a new School Improvement Program for which states initially will compete.

Second, the new Act requires that education programs be designed so that children with disabilities make real progress in the general education curriculum.

Third, states and districts are instructed to bring the shape and the results of the education of children with disabilities into full accord with school reform activities now common among all the states. Two immediate consequences of this requirement are explicit in the Act states must set hard, concrete, system-wide objectives for children with disabilities which states and school districts will meet, such as graduation rates, rates of graduates going on to college, rates of graduates achieving competitive employment, and so forth. Furthermore, in the Act and the Committee Reports it is stated that, beyond those specifics just mentioned, the states (with participation from all of us) must choose objectives to be measured annually and publicly, and reported to the Secretary of Education of the U.S. This represents a lovely advance in accountability!

In the area of accountability, the Act also requires that states include children with disabilities in those assessment programs which states run for children who do not have disabilities. Some of these assessments are longstanding, some of new vintage arising from the school reform movement, but the primary and presumptive requirement is that all children will participate in assessment, with appropriate accommodations. For example, this will cause us to look to the

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An IDEA Q&A With Tom Gilhool

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Education Testing Service for ways children with disabilities can participate in standard current assessment tests such as scholastic achievement tests, and to develop alternative assessment schemes which are equally serious and measure real objective educational achievement. They are to be administered regularly, and reported publicly.

These two requirements - for integration and for an honest-to-goodness educational undertaking which will yield results — are the heart of the guarantees to our children, and are strengthened in lovely ways by this Act.

Question: We're relieved that integration and real education results are prominent in the Act. Are there other provisions of which we should be aware?

Tom Gilhool: Two other changes on the useful side are worth mentioning. The State Advisory Panels, which have been required for some time, now must be composed in their *majority of* parents of people with disabilities or of people with disabilities themselves. The authority of the Panels to see all data that comes to the state — IDEA compliance reviews, civil rights compliance reviews, and so forth — is guaranteed in the statute. These Panels advise the state school officer and the U. S. Secretary of Education with respect to the performance of each state, an authority confirmed and strengthened in the Act. This forum will now be all the more useful.

The second useful provision concerns Title XIX. For some time the Act has made clear that services required by the IEP which are covered by Title XIX, either because the family is of low income or because the child is eligible for SSI, can and should be paid for by Title XIX funds. This Act makes it brilliantly, beautifully, and usefully clear that the state *must* get its head together to use Title XIX for the related services needed by each eligible child. We have an excellent opportunity to increase availability to our children of a full range of supports, assistance, and wrap-around services important for our children's school success. The statute is now written so that services *must* be delivered. Battles between state agencies over who will deliver can't delay delivery; agencies must come together and Title XIX must ultimately pay.

■ ■ ■ ■

The requirements for integration and for honest-to-goodness educational results are at the heart of the guarantees to our children.

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Question: The cornerstone of the IDEA has always been that ALL children with disabilities were entitled to a free and appropriate public education (FAPE). What became of the threat raised during the 104th Congress, that "cessation of services" could become possible for some children with disabilities?

Tom Gilhool: Here we have both good and bad news. The most significant accomplishment of the reauthorization process which culminated in David Hoppe's conversations with all involved parties over this winter and spring is that "cessation of services" has been soundly defeated! *(David Hoppe is Chief of Staff to Senate Leader Trent Lott (R-Miss), and the father of a young child with Down Syndrome.)* The Act firmly and expressly provides that education services may not be interrupted for any child with disabilities. Provisions that may have put those children with disabilities who were regarded by school personnel as disruptive into the shade or the outer darkness were also beaten.

The Consensus Bill of June 1996 would have repealed the "all" from "education for all" and vitiated zero reject. This bill had actually been agreed to by most folks inside the beltway, and passed by the House, before a rebellion in the field took hold over the summer of 1996 and was successful. That's the good news.

The threatening parts of the Act are all in Section 615(k) of the bill. Two are straightforward: they provide that children who knowingly possess dangerous weapons in school and children who possess drugs may be placed in an appropriate interim alternative educational setting, for not more than 45 days. "Dangerous weapons" and "drugs" have fairly well-bounded, tight definitions.

The two provisions we must be watchful about are in 615(k)(2) and 615(k)(4). The first says that any child found by the hearing officer (not the court, as was previously the case) to be "substantially likely to injure himself or others" may be transferred by the school district to an appropriate interim alternative educational placement, and that in such a case parents will have no "stay put rights" (i.e. veto power over the proposed move while the relevant meetings and hearings occur). Any child found to violate a provision of the school's discipline code may also be designated to be transferred to an alternative setting, but in that case "stay put rights" hold. Those are two places at which the Act threatens.

Question: What protections and requirements can families invoke if the district tries to change their child's placement on the grounds that he or she is substantially likely to cause injury?

Tom Gilhool: Any alternative placement is strongly hedged in by the Act itself. It must be one where the child can make progress in the general curriculum, where the I.E.P. can be carried out, and if maladaptive behavior is involved, a professionally acceptable positive behavior plan must be carried out, just as required in the regular education setting. The alternative placement must be "appropriate," which according to the Supreme Court means "reasonably calculated to yield real educational benefits to the child," and most courts of appeal have said that the requirement of appropriateness includes as well the integration requirement and the other central requirements of the Act.

In general, the concept of alternative placement is very limited by their trigger and by the nature of the education

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An IDEA Q&A With Tom Gilhool

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placement itself. The evidentiary standard for "substantially likely to injure self or others" is very high, and the Act requires that proof must be very strong, "beyond a preponderance of the evidence." It is enormously significant that shortly after the Act was passed the president of one of the school principals associations, which were deeply involved in introducing these new provisions, commented that the Act's requirements for alternative placements are so high that very few children will be subject to such assignments.

The requirements for alternative placements codify the standards established by the Supreme Court in *Honig v. Doe*. The Congressional Committee Reports leave no doubt that the strict standards of *Honig*, now govern. They are very strong. The courts have almost never allowed districts to remove a child to alternative placement under *Honig* standards.

The so-called "Gang of Six" - the National School Boards Association, the National Education Association, the American Federation of Teachers, the American Association of School Administrators, the National Association of Secondary School Principals, and the National Association of Elementary School Principals sought "cessation of services" during this reauthorization. Far from accomplishing that goal, one of their representatives was quoted as saying that "None of us any longer believes that homebound instruction is legal."

I believe this is a correct interpretation of the Act, with its fresh emphasis on integration, on well-designed behavior plans, and on extending to the child with disabilities the benefit of the general education curriculum and of the duration and scope of education received by those who are not disabled. This quite plainly means no more handing out a couple hours a day or a week of homebound instruction, since a positive behavior plan is necessarily social and can't be carried out if the child is isolated!

The emphasis on education in integrated, typical settings is underscored by the new emphasis in Part C (formerly Part H) of the Act, which says that Early Intervention services are to be delivered in natural environments, i.e. settings in which the child would be served if he or she did not have a disability, such as a neighborhood nursery school. Those agencies doing segregated Early Intervention are in trouble. This articulation of principles for the very young child further strengthens the integration component of the Act, which overall contains strong words and strong ratification by both Committee Reports supporting education with non-disabled peers.

Question: If any of our families are adversely affected by changes to the IDEA, such as those concerning weapons, drugs, and in particular "substantial likelihood to cause injury to self or others," what can our advocacy organizations do to help?

Tom Gilhool: That's a really important question. In my comments to the Feds on the IDEA regulations, which are now in preparation, I have strongly suggested that Federal regulations should require that for weapons, drugs, and "likelihood to cause injury" there should be regular reporting by districts to states and states to the Feds of any invocations of these provisions of Section 615, as well as a description of the alternative placements proposed.

Short of that — and even with it — it is very important for us to track it. Our advocacy organizations must track the impact of these provisions by maintaining a close and effective network. Through the coming fall and winter we must tighten our advocacy relations and networks, and work together with law centers and law projects across the nation to maintain a score card. We must work to mitigate the down side and to drive the high side.

This is an Act which requires implementation! All schools must come to know what the successful schools already know and are implementing. Whenever a district acts to yank a child, it is a sure measure that the district does not know promising, effective education practices — a knowledge required by the Act. It's an indictment of the district, not the child! Many districts are doing a great job and we can look around to these success stories to prove that it can be done. All districts have the obligation to get their knowledge and practice up to date.

■ ■ ■ ■

Whenever a district acts to yank a child, it's an indictment of the district, not the child!

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Tom Gilhool: These past two years demonstrate to us that prejudice, bigotry, and stereotype are alive in the Congress and to some degree alive in the land, and particularly in the schools. The segregation of people with disabilities was a practice imposed by statutes by all states at the turn of century, and justified as a need to avoid the "menace of the feeble-minded." This meant excluding children from schools and consigning them to segregated institutions for life. The 1975 Education Act was a repudiation of that pattern of bigotry by Congress and by the nation. To understand its meaning, it must be seen in relation to our entire civil rights movement, to the search for equality and justice by racial and ethnic groups and by women as well as by people with disabilities.

Question: Many families found this IDEA reauthorization confusing. Various advocacy groups presented conflicting analyses of proposed changes and different opinions about whether to compromise or delay. Why did our organizations have such difficulty finding a common voice?

Tom Gilhool: Until the grassroots revolution occurred, which was well into the reauthorization process, it was confusing. At a time when the American commitment to equal citizenship is so strongly under attack, it becomes increasingly difficult for anyone to make judgments about what is possible, what is the best we can get, and what's not.

In the summer of '96 the despair in Washington was so overwhelming that compromises were made in good faith. The judgment of advocates "inside the beltway" was that compromise was the

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Positive Behavior Supports and IDEA

**Remarks of
H. Rutherford
Turnbull, III,
Co-Director,
Beach Center on
Families and
Disability,
The University of
Kansas, at the
1997 TASH Annual
Conference**

If ever there were a place and time for celebration, it is here and now. We gather to celebrate a multitude of victories related to students with challenging behaviors. As part of our celebration, we proudly review our own history and our contributions to Individuals with Disabilities Education Act (IDEA), especially as that law relates to positive behavioral support (PBS). But we must temper our celebration and surround it with caution and zeal.

The immediate cause for our celebration is the reauthorization of IDEA and the enactment of two key provisions related to positive behavioral support. One provision requires the IEP team of a student whose behavior disrupts his or her learning or other students' learning to consider, when appropriate, strategies, including positive behavioral interventions, to address the impeding behavior. For me, the basic question, and one that schools will be hard pressed to avoid, is this: When is it not appropriate for schools to consider PBS when behavior impedes learning?

The second provision relates to students who have been disciplined. It requires the Local Educational Agency (LEA) to conduct a functional behavioral assessment and implement a behavioral intervention if it has not already done so, or to review and, if appropriate, revise the student's behavioral intervention plan if the student already has such a plan.

Given these provisions, why is celebration warranted, at least so far as IDEA is concerned?

1. These provisions mark the merger of priests and princes. That is to say, they consolidate the knowledge of the priests--the research community--with the power of the princes --the policy makers.

2. These provisions are emblematic of the victory of positive interventions over aversive interventions. By specifying positive behavioral interventions, IDEA creates at least a rebuttable presumption in favor of those kinds of interventions. Put in another way, it creates at least a rebuttable presumption against nonpositive, or aversive, interventions.

3. These provisions assert a fundamental democratic value, which is that the only proper focus of government is on the individual. The state exists solely to serve the interests of the individual; the individual's claims are the ends, the ultimate objectives, of, and the bedrock justifications for, the state. By declaring that schools must use functional behavioral assessments and positive behavioral interventions, IDEA asserts that it is the individual's development that is the core value. Stated in the alternative, IDEA holds that the convenience of educators and the control of students, too often manifest by indefensible restraints and aversives, are not the proper ends or goals of the state.

4. These provisions codify the principle of "dual accommodations" that is codified by the Americans with Disability Act and Sec. 504 and that also is so ably represented in the 1992 AAMR book redefining mental retardation. Accommodations--that is to say, positive behavioral interventions and supports --are warranted in the school environment whenever they can reduce an individual's challenging behavior and enhance his or her capacities to learn.

5. These provisions symbolize the victory of law over illegality. For years, many of us have argued that a large body of law — not just IDEA but other law as well, particularly constitutional law — requires the state to use only the least restrictive and most positive interventions. IDEA enacts that argument.

6. These provisions extend into federal education law and thereby into state law and local practice the legal doctrines of the right to treatment and, with it, the right to substantive due process. Actually and metaphorically, they free students of all sorts of physical and psychological restraints on their liberties.

7. These provisions strengthen IDEA's seamlessness. The principle of zero reject is buttressed by the discipline provisions and PBS's role there; the principle of nondiscriminatory evaluation is enhanced by the requirement for functional behavioral assessment; and the principle of appropriate education is fortified by the requirement for PBS whenever behavior impedes learning.

8. Finally, these provisions also represent the victory of morality over pure technology. As Anne Donnellan so poetically argued many years ago, technology without values breeds Nazism and its ilk, but values without technology asks us all to wait endlessly for a non-appearing Godot. In IDEA, positive technology combines with the moral value of human development.

As if all of these reasons were not sufficient cause for us to celebrate, there

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Positive Behavior Supports and IDEA

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is yet another. It is TASH's own history, one that perhaps began with the publication in 1986 of a TASH monograph that I was privileged to coauthor. In that monograph TASH railed against aversives and cried out for nonaversive, positive interventions. TASH's own more recent history, namely, its bulldogged but frustrating battle in the B.R.I. case and its important contribution in IDEA's reauthorization, also gives us reason to doff our hats to each other. Without TASH, PBS would not be where it is today.

But, enough of celebration. It is time, now, to take stock of where we are and what else we need to do to assure that positive behavioral supports become more than formal, written law — that they become the law on the street, the practice in the classroom.

1. We must reject the notion, set out in OSEP's explanation of the discipline amendments, that IDEA is correct in "balancing" the rights of students with challenging and discipline provoking behaviors against the interests and rights of other students and staff. The "balancing" argument is wickedly seductive, but we should not succumb to it. Instead, we must argue that, if PBS is embedded into practice for all students who might possibly need it, then the incidence of challenging behaviors and disciplinary sanctions will be diminished and school-wide safety will be increased, all to the benefit of everyone in school. That is what we learn from the work of such people as Rob Horner. There is no ground for "balancing". We must assert that PBS is the safeguard against discipline, a preventive technique, and that all schools and many more students than just those with challenging or impeding behaviors should benefit from it. We need to spread and embed PBS.

2. We must recognize that even our well advanced conceptualization of PBS is elementary. It is of course necessary to focus on the student, on impeding behaviors and on positive/appropriate behaviors. But that focus, though indispensable, is not sufficient. It is also necessary to see PBS as the vehicle for systems-change and policy reform in education (and elsewhere), for environmental alterations, and for training not just of the student but of everyone who is in the student's life. We need to extend the meaning of PBS so that it will change policy, the entire context of the school, and professionals' conduct, not just the student's behavior.

3. We must acknowledge that many families, educators, researchers, and providers are still wedded to the increasingly outdated technology of applied behavior analysis (ABA). Although ABA has much to contribute to functional assessments and positive supports, it is, by itself, a limiting concept and intervention. It does not speak to the whole student/whole life reality that families and students face. And it does not sufficiently lead to lifestyle changes that result in families and students having an enviable life. We must insist on the primacy of PBS over ABA and on the ultimate utility of PBS in helping people "get a life."

4. Technologies and strategies aside, we have to be vigilant against the approach that my colleague Doug Guess (and others) have labelled the "fix it" approach. PBS is superior to ABA, but it too will not be the panacea; there is still too much that we do not understand about human behavior, how environments and policies shape behavior, and the interactions between behavior, environment, and human biology. We need to "sell" PBS, but we should not oversell it as a modern elixir.

5. We must be candid and admit that state laws and local practices and preservice training in our institutions of higher education and in parent training and information centers lag behind IDEA and its PBS provisions. There is yet so much to do to create a PBS-competent cadre of general and special educators, other professionals, and families, and to enable them to put PBS into place as an integral part of the general curriculum and community inclusion to which our students have a legal right and moral claim. We have to press for change in our academies, clinics, and communities.

6. We need to extend the PBS approach beyond federal and state special education law. General education law and practice can benefit from this approach. So, too, can states' mental health and developmental disabilities codes. As the B.R.I. case teaches, we need to reform those laws, too.

7. Finally, we have to assure that TASH and its allied organizations are ever vigilant to war against the old technologies and to advance the cause of PBS. We need energy and strategies to make a sustained and significant difference. The initial battle-to improve IDEA and to codify PBS--is over and won; the implementation battle has not even begun in earnest. The development of a Model State law or technical assistance guideline, now underway at the Beach Center on Families and Disability, is part of the implementation effort. We must be ever watchful, always diligent.

Let me close by thanking all of you who were responsible, in any way, for what we celebrate today. And let me also caution each of us, myself included, by quoting from Shakespeare's Julius Caesar:

"There is a tide in the affairs of men which, taken at the flood, leads on to victory; omitted, all the voyages of our lives are spent in shallows and misery. We are now upon such a tide. "

Indeed we are! We created it, and now the only questions remaining are these: How large a tide is it, how far will it carry us, and who will make sure that the tide will be overwhelming and permanent?

I am sure that each of us will answer that question in our own ways, always positively, and that we will all persevere and prevail in our noble cause. I know I will. I know you will, too.

Call for Nominations: Editor of JASH

The Journal of THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS

The TASH Publications Committee is currently beginning a search for the new Editor of JASH. The term of service for the Editor is three years. Nominations or direct applications are invited from TASH members with the experience and expertise described below. We particularly encourage applications from traditionally underrepresented groups including women, persons with disabilities, and persons from racial or ethnic minorities. The following criteria will be used to select a new Editor for the journal:

1. Previous editorial experience as an Editor or Associate Editor of a scholarly journal in the field;
2. Previous authorship experience and substantial publication record in JASH and other journals.
3. Commitment to TASH policies and ideals.
4. Record of leadership in the area of severe disability, both within and outside of TASH.
5. Openness: willingness to consider new directions and innovative practices in the context of maintaining the Journal's commitment to excellence and scholarship.
6. Research skills: expertise in one or more of the research methods commonly used in the area of severe disability, including within-subject designs, qualitative methods, and/or large-*N* descriptive or experimental methods.
7. General organizational skills: evidence of ability to meet important deadlines and organize major tasks.

Call for Nominees to Serve: JASH Editor Selection Committee

We invite interested TASH members to apply to serve as a member-at-large for the subcommittee that has been formed to make recommendations to the TASH Board for selection of a new Editor of JASH. The members-at-large will work with the Search Committee to review and evaluate applications for the Editor position. Nominations of individuals with disabilities, family members of persons with disabilities and direct service providers are particularly welcome.

Submit nominations to:
Dianne Ferguson, Chair
TASH Publications Operating Committee
Schools Project, STP
1235 University of Oregon
Eugene, OR 97403
FAX: 541-346-5517
email: diannef@oregon.uoregon.edu

This Timeline for Implementation of IDEA '97, is provided to help readers keep track of the effective date(s) for certain parts of the legislation.

TIME LINE FOR IMPLEMENTATION OF IDEA 1997

Effective dates of the amended provisions of the IDEA:

Part A	[General Provisions, including Definitions]
Part B, except as provided below	[Assistance to States Program]

Effective October 1, 1997:

Part D, except as provided below	[State Improvement Grants and IDEA discretionary programs – Parts C, E, F, and G of the current IDEA are repealed effective October 1, 1997. NOTE, however: The Act gives the Secretary the authority to use funds appropriated under the new Part D to make continuation awards for projects funded under section 618 and Parts C through G of the IDEA as in effect on September 30, 1997.]

Effective January 1, 1998:

Section 661(g)(1) and (2)	[Requirements for the Secretary to establish and use a standing panel and peer review panels for reviewing applications under Subpart 2 of Part D (IDEA discretionary programs)]

Effective July 1, 1998:

Section 612(a)(4)	[IEP - State eligibility condition - the IEP requirements of the IDEA as in effect before enactment of the IDEA Amendments of 1997 remain in effect until July , 1998]
Section 612(a)(14)	[CSPD - State eligibility condition - the CSPD requirements of the IDEA as in effect before enactment of the IDEA Amendments of 1997 remain in effect until July 1, 1998]
Section 612(a)(16)	[Performance Goals and Indicators - State eligibility condition]
Section 614(d)(1)-(5)	[IEP definitions; requirement that programs be in effect; development of IEPs; review and revision of IEPs; and failure to meet transition objectives - the IEP requirements of the IDEA as in effect before enactment of the IDEA Amendments of 1997 remain in effect until July 1, 1998]

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INCLUSION TIMES
FOR CHILDREN AND YOUTH WITH DISABILITIES

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Part C: Infants and Toddlers with Disabilities

TASH acknowledges the assistance of our colleagues at the National Information Center for Children and Youth with Disabilities (NICHCY) in providing this side-by-side comparison of Part C of IDEA. To obtain a copy of the NICHCY News Digest in which this information appeared, call 1-800-695-0285 (Voice/TTY) or send an e-mail to: nichcy@aed.org

Remember Part H? The portion of the law that set out the requirements for educational services for infants and toddlers with disabilities? It's been renamed Part C and we've included a brief list of the notable changes.

★ *Change within IDEA:* In the old legislation, the Infants and Toddlers Program requirements were located in Part H, so that early intervention was often referred to as the Part H program.	★ *Change within IDEA:* Under the new law, the Infants and Toddlers Program requirements are located in Part C. There will no longer be a Part H. These changes take effect July 1, 1998.
★ *Findings and policies:* The old IDEA included findings related to the need to enhance the development of infants and toddlers with disabilities.	★ *Findings and policies:* IDEA 97 maintains prior findings and modifies one of its purposes from developing an early intervention "program" to developing a "system that provides early intervention services." Also added is the purpose "to encourage States to expand opportunities for children under 3 years of age who would be at risk of having substantial developmental delay if they did not receive early intervention services." [Section 631(b)(1) and (4)]
★ *Definitions:* A definition of "at-risk infant or toddler" did not exist in old law.	★ *Definitions:* The new law maintains previous definitions and additionally defines "at-risk infant or toddler" as: "...an individual under 3 years of age who would be at risk of experiencing a substantial developmental delay if early intervention services were not provided to the individual." [Section 632(1)]
★ *General requirements:* The old law outlined a series of requirements, including a timetable for implementation of an early intervention system.	★ *General requirements:* The new law maintains previous requirements and clarifies that the identification of each family's needs must be "family-directed." [Section 635(a)(3)] The implementation timetable has been dropped. A requirement is added that a State policy must be in effect that ensures availability of early intervention services. [Section 635(a)(2)]
★ *Natural environments:* No similar provisions existed in the old IDEA.	★ *Natural environments:* The new law requires policies and procedures that ensure: "(A) to the maximum extent appropriate, early intervention services are provided in natural environments, and (B) the provision of early intervention services for any infant or toddler occurs in a setting other than a natural environment only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment." [Section 635(a)(16)]

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Infants and Toddlers with Disabilities

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★ *Personnel standards:* Similar requirements existed for the Infant and Toddler Program.	★ *Personnel standards:* Similar requirements exist under the new law for the Infant and Toddler Program. [Section 635(a)(8)]
★ *IFSP:* The prior legislation outlined requirements for the development of individualized family service plans (IFSP).	★ *IFSP:* The new law maintains similar requirements, with the additional requirement that a justification be included 41 of the extent, if any, to which services will not be provided in a natural environment." [Section 636(d)(5)]
★ *Procedural safeguards:* The old law outlined procedural safeguards to be included in the statewide system.	★ *Procedural safeguards:* The new law maintains prior requirements. The prohibition on who may not serve as a surrogate parent is expanded to include individuals or employees of providers of early intervention services. [Section 639(a)(5)] Right to mediation, as delineated under Part B, applies to Part C as well, with Part B references to FAPE being considered as references to early intervention services. [Section 639(a)(8)]
★ *State Interagency Coordinating Council:* The old law required a State to establish an ICC according to listed specifications.	★ *State Interagency Coordinating Council:* The new IDEA maintains prior requirements regarding establishment, composition, meetings, management authority, and function of ICCS. The number of members is now left to the State to determine. [Section 641]

> **"We can see a future where we finally put an end to the divisive, false argument that goes, 'something for your child means something less for my child.' If the American experience tells us anything, it is that expanding opportunity lifts us all up. Let us be a proud nation that takes responsibility for all our children."**
>
> **— Judith Heumann, Assistant Secretary of OSERS**

An IDEA Q&A With Tom Gilhool

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best they could get. The situation began to change when others, chiefly "beyond the beltway" and across the country, came to the judgment that asking whether preservation of the IDEA was possible or not was the wrong question, and that we must do better.

The strength of the parent and family movement was sufficient to change the parameters in Washington. It was close — a 51 to 48 vote on the motion to table the reauthorization during the 104th Congress — but successful!

Question: If you could sum up in a few words what we've learned from this IDEA reauthorization, and what our families and advocacy groups should now remember, what thought would you leave us with?

Tom Gilhool: Vaclav Havel, in what has come to be called Czechoslovakia's "Velvet Revolution," was once asked what lessons he had learned during the difficult, unlikely process of opening his country to democracy after years of communist dictatorship. He replied, "The clearest lesson is that in times and places where citizenship is devalued, citizens must first tell the truth as they see it and act upon it, rather than trying to calculate whether their actions will succeed. For if they do, they will not act."

GETTING INFORMATION ABOUT IDEA:

To read or download the text of the law and the House and Senate Conference reports, go to http://www.thomas.loc.gov on the Internet and follow directions. The reports are 105-95 (House) and 105-17 (Senate). *We recommend you look at the House report first, both reports are similar.* The law is PL 105-17, The Individuals with Disabilities Education Act Amendments of 1997.

Information from the U.S. Department of Education, Office of Special Education Programs, has stipulated a requirement that State Advisory Panels include representation from a majority of individuals with disabilities and parents of children with disabilities.

State Advisory Panel

Section 612(a)(20) - Public Participation. This section requires that, prior to the adoption of any policies and procedures needed to comply with Section 612 (including any amendments to such policies and procedures), there are public hearings, adequate notice of the hearings, and an opportunity to comment available to the general public, including individuals with disabilities and parents of children with disabilities.

Section 612(a)(21) - State Advisory Panel. This section retains the requirements of Section 613(a)(12) in the prior law regarding the establishment of a State Advisory Panel, with the following changes:

(1) A requirement is added that the advisory panel must include representatives of private schools and public charter schools, and representatives from the State juvenile and adult corrections agencies;

(2) A requirement is added that a majority of the members of the panel must be individuals with disabilities or parents of children with disabilities;

(3) The section retains the requirement that the advisory panel must comment publicly on any roles or regulations proposed by the State regarding the education of children with disabilities, but does not retain the requirement in prior law that the advisory panel must comment publicly on the procedures for distribution of funds under Part B;

(4) A requirement is added that the advisory panel must advise the state educational agencies (SEA) in developing corrective action plans to address findings in Federal Part B monitoring reports; and

(5) A requirement is added that the advisory panel must advise the SEA in developing and implementing policies relating to the coordination of services for children with disabilities.

Section 612(a)(22) - Suspension and Expulsion Rates. This section establishes requirements for the examination of data regarding rates of long-term suspensions and expulsions of children with disabilities.

(1) The SEA must examine data to determine if significant discrepancies are occurring in the rate of long-term suspensions and expulsions of children with disabilities—(a) among LEAs in the State; or (b) compared to such rates for nondisabled children within such agencies.

(2) If such discrepancies are occurring, the SEA must review and, if appropriate, revise (or require the affected State or local educational agency to revise) its policies, procedures, and practices relating to the development and implementation of IEPs, the use of behavioral interventions, and procedural safeguards, to ensure that such policies, procedures, and practices comply with the Act.

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DISCRETIONARY PROGRAMS OF IDEA '97

Discretionary programs are those special programs or "enhancements" that really make IDEA work. Teacher preparation, early childhood (Part C), and parent training centers are examples of some of the discretionary programs funded under IDEA.

Prior to the reauthorization of IDEA, OSEP supported discretionary projects under 14 different authorities. IDEA now combines these 14 authorities into 7 authorities under Part D, *National Activities to Improve Education of Children with Disabilities*, of the new law.

Under Part D, Subpart 1:

1. **State Improvement Grants** (Part D, Sec. 651-656), which are awarded to state educational agencies (SEAs), and of which 75% of funds must be used for professional development activities unless the Secretary grants a waiver to a State;

Under Part D, Subpart 2:

2. **Research and Innovation to Improve Services and Results for Children with Disabilities** (Part D, Chapter 1, Sec. 672), which will fund new knowledge development, integration of research and practice, and improving professional knowledge.

3. **Personnel Preparation to Improve Services and Results for Children with Disabilities** (Part D, Chapter 1, Sec. 673), which will fund projects dealing with low incidence disabilities, leadership preparation, projects of national significant, and those dealing with high incidence disabilities.

4. **Studies and Evaluations** (Part D, Chapter 1, Sec. 674), which will include national assessment studies, preparation of OSEP's Annual Report to Congress, and providing technical assistance to local educational agencies (LEAs). Funding for this section comes from a portion of funds appropriated under Parts B, *Assistance for Education of All Children with Disabilities*, and C, *Infants and Toddlers with Disabilities*, of the law.

5. **Parent Training and Information Services** (Part D, Chapter 2, Sec. 682-684), which includes authorization for three activities: Parent Training and Information Centers, Community Parent Resource Centers, and Technical Assistance for Parent Training and Information Centers.

6. **Coordinated Technical Assistance and Dissemination of Information** (Part D, Chapter 2, Sec. 685), which includes authorization for technical assistance and dissemination to improve early intervention, educational and transitional services and results for children with disabilities and their families, and address systemic-change goals and priorities.

7. **Technology Development, Demonstration, and Utilization** (Part D, Chapter 2, Sec. 687), under which authorized activities include conducting research and development, demonstrations, providing technical assistance, communicating information on technology, captioning and descriptive video services.

Projects supported under the *State Improvement* authority are administered by OSEP's *Monitoring and State Improvement Program* (MSIP), while administration of projects supported under the *Coordinated Technical Assistance, Support, and Dissemination of Information* authority are shared by MSIP and the *Research-to-Practice Division*. Projects supported under the remaining five authorities are administered by OSEP's *Research-to-Practice* Division.

The new law authorizes the Secretary of Education to use funds appropriated under Part D (*National Activities to Improve Education of Children with Disabilities*) to make continuation awards to projects funded under the previous law, if your project period extends beyond Fiscal Year 1998 (school year 1997-1998).

In addition to continuing grant applications, other areas of interest to your work include changes in the new law that affect proposed priorities, peer review procedures, and the comprehensive planning process.

Process for Fiscal Year 1998 Priorities

We are currently in the process of developing priorities for Fiscal Year 1998 based on the language of the new law. The Department has the authority to finalize these priorities without receiving public comment. However, as previous priorities have benefited from stakeholder comment, we are now developing a process to solicit you, and other stakeholders' input on the priorities proposed for Fiscal Year 1998.

Standing Plans

In accordance with the new legislation, we will be implementing certain changes to our peer review procedures over the next year. Beginning in January 1998, we will appoint standing panels to evaluate applications under Subpart 2, Part D, of IDEA. These panels will consist of individuals with appropriate expertise and background, who will be asked to serve on a panel for no more

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Discretionary Programs of IDEA

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than three consecutive years. We anticipate that, as in years past, some of you may participate in this grant application review process. We will continue to keep you updated as our plans for standing panels are developed and finalized this summer and fall.

Comprehensive Planning for Discretionary Programs

As required by IDEA, OSEP is establishing a comprehensive planning process for the discretionary activities administered by the *Research-to-Practice Division*. This process will essentially continue the work, authorized under the previous law, of stakeholders who helped us articulate program agendas for several discretionary programs, including the *National Personnel Agenda, Program for Children and Youth with Serious Emotional Disturbance, Program for Children with Severe Disabilities, Special Studies Program, and the Technology, Educational Media and Materials for Individuals with Disabilities Program*. The new comprehensive planning process will continue to involve "individuals with disabilities, parents of children with disabilities, appropriate professionals, and representatives of State and local educational agencies, private schools, institutions of higher education, other Federal agencies, the National Council on Disability, and national organizations with an interest in, and expertise in, providing services to children with disabilities and their families" (Sec. 661(a)(2)(A) to (D)). We will be soliciting stakeholder input and involvement in this process shortly after the start of the next fiscal year, October 1, 1997.

The reauthorization of IDEA has continued a long history of support for discretionary projects that contribute to improved results for children with disabilities and their families. We will continue to keep you informed of our progress and look forward to your ongoing involvement, participation, and support as we work to implement the new law in the coming months.

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featuring

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Schedule: Keynote Address

Topical Sessions

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- The Issue of Behavior
- Modifications, Adaptations, Interventions and the General Ed. Curriculum
- Community Inclusion

Lunch (provided)

Cracker Barrel Sessions (by age level)
Discussion of Inclusive Education Issues and Sharing Successes

- Preschool/Early Childhood
- Elementary School
- Middle School
- High School Age and Beyond

Wrap up: Norman Kunc

Questions/ Registration Information: Candee Basford (937) 695-0169
Marty Oppenheimer (614) 262-4545

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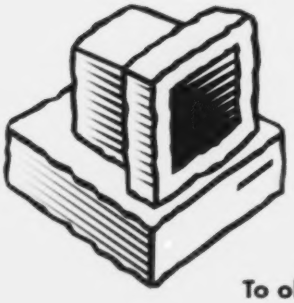
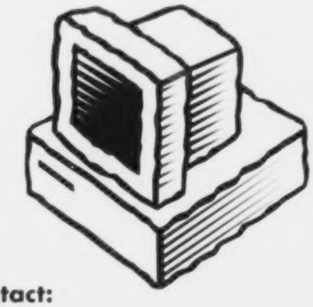


Resources for Additional Information on the 1997 IDEA Amendments



To obtain a copy of the law and the draft regulations, contact:

Office of Special Education and Rehabilitative Services (OSERS), Clearinghouse on Disability Information, Room 3132, Switzer Building, 330 C Street, S.W., Washington, D.C. 20202-2524. Telephone: 202-205-8241 (V/TTY). URL: http://www.ed.gov

* * * *

A copy of the Notice of Proposed Rulemaking (NPRM), appears on the Federal Register home page at [http://www.access.gpo.gov/su_docs]

* * * *

TASH is interested in hearing from its readers about your personal and/or professional experiences with implementation of the provisions of the 1997 IDEA Amendments. Information may be sent via e-mail to: IDEA97@tash.org

* * * *

A live interactive teleconference about community efforts to improve teaching and learning:

SATELLITE TOWN MEETING:
"Serving Students with Disabilities: What Families, Schools and Communities Need to Know"
Tuesday, January 20, 1998 – 8:00-9:00 PM (Eastern time)

The U.S. Department of Education's January Satellite Town Meeting will look at ways that families, educators and communities can work together to improve the quality of education for students with disabilities and provide schools with the tools to assess what all children are learning. The discussion will include the recent amendments to the Individuals with Disabilities Education Act (IDEA).

Additional information is available by calling 1-800-USA-LEARN, or by e-mail at Satellite_Town_Meeting@ed.gov

CONGRATULATIONS

to the following newly elected members of the

★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★

TASH Executive Board

Mike Auberger (re-elected)
Donna Gilles
Jay Klein
Tim Knoster
Deb Kunz
Joe Wykowski

WHAT DOES IDEA '97 SAY ABOUT Evaluations, Eligibility, IEPs & Placements?

TASH gratefully acknowledges the assistance of Rud Turnbull of the Beach Center at the University of Kansas for allowing us to reprint excerpts from the article written by Rud with Kate Rainbolt and Amy Buchele-Ash. The article highlights the significant new safeguards for students and the rights of parents to participate in educational decision-making.

A copy of the full paper can be obtained from the Beach Center by calling 913-864-7600 (Voice/TDD).

IDEA Sec 614 basically continues the prior IDEA protections in nondiscriminatory evaluation, individualized education and least restrictive environment placement, with significant new safeguards for students and new rights of parents to participate in educational decision making.

EVALUATIONS (SEC. 614(B) AND (C))

Parent consent to evaluation. The initial evaluation still requires notice to parents and parental consent.

Subsequent evaluations continue to require notice to parents, but they now also must be based on parental consent.

Nonconsent. If the Local Educational Agency (LEA) has taken reasonable measures to secure parent consent and if the parent has failed to respond to the request for consent, the LEA may then evaluate the student. Also, if the parents refuse to consent, the LEA may use the mediation or due process procedures to secure consent or permission to evaluate.

Effect of consent. Consent to an evaluation is not consent for placement into special education. That consent must be secured separately.

Purposes of evaluation. There are two purposes: first, to determine whether the student has a disability; and, second, to determine the student's educational needs.

Reevaluations. Reevaluations must occur at least once every three years, but may occur if "conditions warrant" or if the student's parents or teachers request a reevaluation.

Evaluations before change of eligibility and exclusion from Free and Appropriate Public Education (FAPE). An LEA must comply with the nondiscriminatory evaluation requirements before it may determine that a student is no longer eligible for special education.

Membership on the evaluation team. The evaluation team (which also is the IEP team, thereby assuring a link between evaluation, program, and placement) consists of

- the student's parents
- at least one regular education teacher of the student, if the student is or may be participating in the regular education environment
- at least one special education teacher or (where appropriate) a provider of special education to the student
- a representative of the local agency who is qualified to provide or supervise specially designed instruction to meet the unique needs of students with disabilities and is knowledgeable about general curriculum and the availability of local agency resources
- an individual who can interpret the instructional implications of evaluation results (who may already be a member of the team), and
- at the parents' or agency's discretion, other individuals who have knowledge or special expertise (including related services personnel), and the student (when appropriate).

Nondiscriminatory evaluation standards and procedures. All evaluation must continue to conform to the present nondiscriminatory safeguards, namely—

- no racial or cultural bias in tests or materials
- administration in native language or mode of communication
- validated standardized tests administered consistent with instructions by developer and by qualified personnel
- no single procedure used as the sole criterion.

Parent participation in evaluation. All evaluations, however, must incorporate new safeguards for the parents:

- the evaluation team must include the parent in addition to qualified professionals
- the parents must receive a copy of the evaluation report and documentation of student eligibility for special education
- the parents may submit and require the evaluation team to consider evaluations and information that they initiate.

Enriched, more extensive evaluation. All evaluations also must incorporate new safeguards for the students, and the evaluation team must—

- use a variety of assessment tools and strategies to gather relevant functional and developmental information to determine whether the student has a disability and the content of the student's IEP, including information that enables the student to participate in the general curriculum or, for preschoolers, appropriate activities
- use technically sound instruments to assess the relative contribution of cognitive and behavioral factors, in addition to physical or developmental factors
- use assessment tool and strategies that provide relevant information that directly assists the term to determine that the student's educational needs are provided (i.e. satisfied)
- review existing evaluation data, including current classroom-based

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assessments and observations and teacher and related services' providers observations

- identify what additional data they need to determine:
  - (a) Does the student have a particular category of disability and does the student continue to have that disability?
  - (b) What are the student's present levels of performance and educational needs?
  - (c) Does the student need (or continue to need) special education and related services?
  - (d) What, if any, additions or modifications to the student's special education and related services are needed to enable the student to meet the measurable annual goals of his or her IEP and to participate as appropriate in the general curriculum?
- Notify the parents that they do not need additional data to determine whether the student remains eligible for special education and let the parents know why they reached that conclusion and that the parents may appeal it via mediation or due process.
- Administer or have administered by the local agency all tests and other evaluation materials that are needed to produce the required data, but if the team determines that it does not need additional data, it must so notify the student's parents, say why it reached that conclusion and not collect additional data unless the parents request it to do so.

SIGNIFICANCE OF CHANGES

The new provisions

- substantially increase parent participation rights
- create a team that includes both the parents and the student, and also a host of other individuals who are responsible for not just evaluation but also for program delivery and monitoring and for placement decisions
- thereby link the evaluation to the IEP and program
- emphasize that the evaluation must also take into account the student's participation in the general curiculum (a pro-LRE provision)
- require classroom-based data to be generated and considered and thus target not only the student's behavior but also the capacity of the staff to deliver effective general and special education services
- focus equally on four domains of the student, namely, cognitive, behavioral, physical, and developmental factors, thereby providing data that can be used to develop effective interventions (including those that prevent suspension and expulsion) and that incidentally assess the effectiveness of the services that the student receives, and
- require the team to use "tools and strategies" that indicate whether the school is meeting the student's educational needs, thereby adding yet another accountability provision in favor of the student and linking evaluation and intervention to general school improvement initiatives

> ***"Since the passage of IDEA, 90 percent fewer developmentally disabled children are living in institutions, hundreds of thousands of children with disabilities attend public schools and regular classrooms; three times as many disabled young people are enrolled in colleges and universities; twice as many young Americans with disabilities in their 20s are in the American workplace. We have to continue to push these trends, to do everything we can to encourage our children with disabilities not only to dream of doing great things, but to live out their dreams."***
>
> ***— President Bill Clinton at the signing ceremony for the IDEA Amendments (June 1997)***

INDIVIDUALIZED EDUCATION: THE IEP (SEC. 614(D))

The IEP itself is redefined, and now includes the elements of the present law as well as new elements. The "carryover" and "new" elements are the following.

Performance and inclusion. Statement of present levels of educational performance ("carry over") but these must include a new element i.e., how the student's disability affects his/her involvement and performance in the general curriculum or, for a preschooler, appropriate activities (a pro-LRE provision).

Annual goals and inclusion. Statement of measurable annual goals related to two matters:

- a new element, i.e., "benchmarks or short-term objectives" related to meeting the student's needs that result from his/her disability to enable him/her to be involved and progress in the general curriculum (another pro-LRE provision)
- a carry over element i.e., meeting the student's other education needs that are related to the disability.

Service provision and inclusion. A statement of services to be provided (a general "carry over") but, as new elements, the statement must identify two types of services, namely: (a) special education and related services, and (b) supplementary aids and services. It must also describe the program modifications or supports that the school will provide to its own staff so that the student may achieve three new benefits, namely:

- advancement appropriately toward attaining the IEP annual goals
- involvement and progress in the general curriculum and participation in extracurricular and other nonacademic activities
- education and participation with other students (those with and without disabilities)

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The IEP also must—

- explain the extent, if any, the student will not participate with students who do not have disabilities in the regular class and in extracurricular and other nonacademic activities
- state what modifications in state or district-wide assessments will be made so the student can participate in those assessments and why the student will not participate in them and otherwise been assessed (if the student is to be exempted from the assessments)
- state when the services and modifications will begin how often they win be delivered, where they will be delivered, and how long they will last.

Transition. At age 14 and annually afterwards, the IEP must state the student's transition services needs. At age 16 or younger if the IEP team determines it to be appropriate, the IEP must have a statement of needed transition services and interagency responsibilities or any other needed linkages.

Age of majority. A year before the student attains the age of majority, the IEP must have a statement that the student has been informed of his or her IDEA rights that will transfer from the parents to the student upon reaching the age of majority (see Sec. 615(M)).

Measuring progress. The IEP must contain a statement of how the student's progress toward annual goals will be measured and how the parents will be regularly informed (as often as parents of students without disabilities are informed) about the student's progress; the goals relate to meeting the student's disability-caused needs that enable the student to be involved in and progress in the general curriculum and meeting each of the student's other disability-caused needs.

Timing. The IEP team must develop an IEP and have one in effect at the beginning of each school year (the effective date is a new requirement).

Mandatory factors to be considered. The team must consider the following:

- the student's strengths
- the parents' concerns
- the results of all evaluations
- special factors, namely
- for a student whose behavior impedes his or others' learning appropriate strategies, including positive behavioral interventions, strategies, and supports, to address that behavior
- for a student with limited English proficiency, the student's language needs
- for a student who is blind or visually impaired, the use of Braille or other appropriate reading and writing media
- for a student who is deaf or hard of hearing, the student's language and communication needs, opportunities for direct communications with peers and professionals in the student's language and communication mode, academic level, and full range of needs
- for all students, whether assistive technology devices and services are appropriate.

Regular education participation. The IEP team consists of a regular educator who, to the extent appropriate, must participate in developing the IEP, especially by determining what are the appropriate positive behavioral interventions and strategies and supplementary aids and services, program modifications, and support for school personnel.

Parent membership. Also, the agency must ensure that the student's parents are members of any group that makes placement decisions.

Annual review and revision. At least annually and more often as warranted, the IEP team must review the IEP to determine whether the student's annual goals are being achieved.

The team must then revise the IEP as appropriate to address

- the student's lack of expected progress toward annual goals and the general curriculum
- the results of any reevaluation
- information provided by the parents
- the student's anticipated needs
- any other matters.

The regular education teacher must participate, as appropriate, in the annual review and revision.

PROCEDURAL SAFEGUARDS AND PROCEDURAL DUE PROCESS

Since one of the purposes of the federal presence in special education has always been to safeguard parents' and students' rights, Sec. 615 reiterates IDEA's traditional rights but adds new provisions, some of which strengthen those rights but others of which create exceptions to them.

Parent rights. Sec. 615 restates the following previous rights of parents.

Notice. Parents have the right

- to be notified whenever an agency proposes or refuses to change the student's identification, evaluation, or placement, or the provision of FAPE
- to have the notice contain certain information
- to have the notice be in their native language
- to receive a copy of the procedural safeguards
- to have that copy at certain times, namely, at initial referral for evaluation and at each IEP and revaluation

Content of Notice, generally. All notices to parents must contain seven separate elements:

1. a description of the action the LEA wants to take or refuses to take
2. an explanation of why the LEA reached that decision
3. a description of any other options that the LEA considered and why the LEA rejected each of them
4. a description of each evaluation procedure, test, record, or report that the LEA used as a basis for its decision
5. a description of any other factors relevant to the LEA's decision
6. a statement that the parents have certain procedural safeguards (i.e., due process protections) and the notice is not an initial referral for evaluation, the means by which they

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can obtain a copy of a description of the procedural safeguards, and

7. the sources the parents may contact to obtain assistance in understanding Part B (student and parent rights).

Procedural safeguards notice. An LEA must give the parents a special notice, called the "Procedural Safeguards Notice," on at least these three occasions:

1. Whenever an LEA proposes an initial referral,
2. Whenever the LEA notifies the parents that there will be an IEP meeting and whenever it reevaluates the student, and
3. Whenever the LEA receives from a parent a complaint that triggers the mediation or due process hearing process (and arguably whenever the LEA itself registers a complaint that triggers these proceedings).

Form of procedural safeguards notice. The notice must be written in the parents' native language (unless it is clearly not feasible to do so), must be written in an easily understandable manner, and must fully explain the procedural safeguards available under Sec. 615 and its regulations.

Content of procedural safeguards notice. The notice must relate to

- independent education evaluation
- prior written consent
- parental consent
- access to educational records
- opportunity to present complaints
- the student's placement during due process hearings
- the procedures related to students who are placed into an interim alternative setting
- the requirements for unilateral placement by parents into a private school at public expense
- mediation
- due process hearings, including requirements for the parent to disclose all evaluation results and recommendations at least five days before the hearing
- state-level appeals (appeals to the state educational agencies (SEA) from a local hearing officer)
- civil actions (right to sue in federal or state courts after an unsuccessful appeal at the SEA level), and
- attorneys' fees.

> ***"We are a better country because disabled Americans have used IDEA to tell us a story that all Americans need to hear – that no child should be shunted aside because we do not think that they can learn – that every young person should be given the skills that they need in order to live independently – and that every American with a disability has a contribution to make to building up our society."***
>
> ***— Richard W. Riley, Secretary, U.S. Department of Education***

Access. Sec. 615 continues to grant parents the right to have access to all records about the student.

Due process complaints. Parents continue to have the right to have the opportunity to present complaints about the student's identification, evaluation, placement, and provision of FAPE.

Impartial due process hearing. Parents continue to have the right to have access to an impartial due process hearing and to have specified hearing rights, namely

- to discover, and, with that right, to have to reveal to the agency, at least five days before a hearing, all evaluations completed by that date and the recommendations based on the evaluations that will be made at the hearing
- to be represented by counsel
- to present evidence, confront, examine, cross-examine, and compel the attendance of witnesses
- to have a written or electronic verbatim record of the hearing
- to have a written or electronic verbatim findings of fact and a decision on the issues, which decision must be transmitted to the state agency and the State advisory panel
- to appeal to the state agency and then to a federal or state court, and to have the court receive the records of the due process hearings and state-level appeals, hear additional evidence, and base its decision on the preponderance of the evidence
- to recover attorney fees if he/she prevails
- to have the student "stay put" during any due process hearings or appeals or during any trials and appeals
- to examine all records relating to the student, and
- to present complaints with respect to any matter related to identification, evaluation, placement, or provision of FAPE.

Parent participation. Sec. 615 adds a new protection: parents have the right to participate in meetings that deal with student identification, evaluation, and placement, and the provision of FAPE.

Parent duties. Sec. 615, however, imposes new duties on parents and limits their previous rights. Parents or their attorneys must give the state or local agency notice (which must remain confidential) that

1. identifies the student
2. describes the nature of the problem related to any proposal by an agency to change, or any refusal by an agency, to change the student's identification, evaluation, placement, or provision of FAPE, and
3. proposes a resolution of the problem(s) to the extent known and available to the parents at that time.

Mediation. Parents must be offered an opportunity to engage in mediation and, if they decline, they must meet with a disinterested party (a parent training and information center, community parent resource center, or other alternative dispute resolution entity) to be encouraged during that meeting to use mediation and be told its benefits.

Mediation must be voluntary, may not deny or delay a parent's or student's rights,

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Regulations for Implementing IDEA '97

The changes in IDEA '97 require the U.S. Department of Education to write new regulations for implementing the law. The Notice of Proposed Rulemaking (draft regulations) was published on October 22, 1997. After a 90-day period of public comment, final regulations will be issued, probably sometime next summer.

Public hearings on the draft regulations were conducted in October and November at locations across the country. Many TASH members provided oral testimony. The TASH Education Interest and Action Committee is working on providing written input prior to the January 20, 1998 deadline. We will also issue a statement of the TASH position early in January. This statement will be distributed as widely as possible. The statement will also be published on TASH's website, www.tash.org. In addition, we will make the statement available upon request during the period January 8-20, 1998.

Please call Marcie Roth at 410-828-8274, ext. 104 if you would like to comment on the proposed regulations. It will be vitally important for TASH members to comment on what you think is acceptable or unacceptable in the regulations and what you think is missing and should be part of the regulations.

The proposed regulations are available on the Internet at: http://ocfo.ed.gov/fedreg/proprule.htm. You may also obtain a copy of the Notice of Proposed Rulemaking through one of several other sources:

Call 1-800-USA-LEARN to request a copy

Call (202-512-0000) or write the Government Printing Office, Superintendent of Documents, P.O. Box 37195-7954,
Pittsburgh, PA 15250

Call the Federal Depository Library or Government Printing Bookstore in your area.
To locate the library or bookstore nearest to you, call 202-512-1530.

Individuals with disabilities may obtain the Notice of Proposed Rulemaking in an alternate format (Braille, large print, audiotape, computer diskette) by contacting:

Katie Mincey, Director of Alternate Formats Center, Telephone: 202-205-8113 or E-mail: katie_mincey@ed.gov

Materials Available

Materials are available regarding participatory research, the facilitation of friendship for students with severe disabilities, the assessment of social skills, attitudes toward inclusion, consultation models to support integrated educational services for students with challenging behaviors, collaborative teaching and educational learning, positive approaches for challenging behaviors, and the inclusion of students with severe disabilities in general education.

For a list of publications and measures, write or call:
Gerald M. Mager, Ph.D., Special Projects, Teaching and Leadership,
150 Huntington Hall, Syracuse, New York 13244-2280
or call 315-443-1881 and ask for Wyvonnia Melton.

HIGHLIGHTS OF THE DISCIPLINE PROVISIONS OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT AMENDMENTS OF 1997

PRODUCED BY THE CENTER FOR LAW AND EDUCATION, BOSTON, MA

The Individuals with Disabilities Education Act (IDEA) Amendments of 1997, Pub. L. 105-17, 111 Stat. 37 (June 4, 1997), made many significant changes in the rights of children with disabilities in the context of school discipline. The following summarizes the most critical provisions of the new law as it pertains to discipline, including disciplinary exclusion, the filing by schools of crime reports and delinquency petitions, and the rights of youth incarcerated in adult facilities. It is not a comprehensive discussion of the discipline rights of students with disabilities (which includes rights under Section 504 of the Rehabilitation Act of 1973, and other laws), nor of all the discipline issues raised by the new IDEA.

1. Free Appropriate Public Education (FAPE) for Students Who Have Been Suspended or Expelled [20 U.S.C. Section 1412(a)(1)][1]

The new law explicitly states that all children with disabilities are entitled to a free appropriate public education, including those who have been suspended or expelled from school. The statute makes no distinction between short-term (10 days or less) and long-term (more than 10 days) suspensions. Nonetheless, the U.S. Department of Education has taken the position that the right to FAPE is triggered only when a student has been suspended for more than 10 days in a school year.[2]

2. Permissible Suspensions and Expulsions (20 U.S.C. Subsection 1415(k)(4), (5)]

Students with disabilities may be suspended for more than 10 days in a given school year or expelled to the same extent as non-disabled students if the behavior in question was not a manifestation of disability. The statute may also be interpreted to require a manifestation determination for suspensions of 10 days or less. The U.S. Department of Education has taken the position that a manifestation determination is not required unless suspension for a total of 11 days or more in a given school year is contemplated.[3]

3. Manifestation Determination [20 U.S.C. Subsection 1415(k)(4)(B), (C)]

The manifestation determination is made by the IEP team, which includes parents, and other "qualified personnel." The team must find that the behavior was a manifestation of disability if: (1) in relation to the behavior, the child's IEP or placement was inappropriate; OR (2) in relation to the behavior, special education services, supplementary aids and services, and behavior intervention strategies were not implemented in a manner consistent with the child's IEP and placement; OR (3) the child's disability impaired his or her ability to understand the impact and consequences of the behavior; OR (4) the child's disability impaired his or her ability to control the behavior.

4. Behavioral Assessments and Intervention Plans [20 U.S.C. Section 1415(k)(1)(B)]

Whenever school officials remove a child from his or her current educational placement, including for ten days or less, the school system must conduct a functional behavioral assessment of the child and develop a behavioral intervention plan. If such an assessment already has been done and a plan developed, the IEP team must review the plan and modify it as necessary to address the behavior that prompted the removal. While the statute clearly provides that these rights apply in suspensions of any length, the U.S. Department of Education, without legal analysis, has taken the position that schools need not conduct assessments or develop or review plans unless the child will be excluded from his or her current placement for a total of 11 days or more during a given school year.[4]

5. Dangerous Weapons and Drugs [20 U.S.C. Subsection 1415(k)(1)(A)(ii), (k)(6)(B)(ii), (k)(10)(A), (D)]

School personnel may unilaterally place a child in an "appropriate interim alternative educational setting" for the same amount of time a non-disabled child would be subject to discipline, but not for more than 45 days, if the child "carries" certain dangerous weapons to school or a school function, OR knowingly possesses or uses illegal drugs, OR sells or attempts to sell a controlled substance at school or a school function.[5] A child may not be removed to an interim alternative educational setting unless (1) keeping the child in the current placement is substantially likely to result in injury to the child or others; AND (2) reasonable efforts to minimize the risk of harm in the current placement, including the use of supplementary aids and services, will not be effective; AND (3) the interim alternative educational setting meets statutory

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HIGHLIGHTS OF THE DISCIPLINE PROVISIONS OF IDEA '97

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requirements (see below).[6] Prior to removing a child to an interim alternative educational setting, the school must also consider the appropriateness of the child's current placement.[7]

If the school has determined that the child's conduct was not a manifestation of disability, the child may be suspended or expelled for the same period of time for which non-disabled children are disciplined for the same conduct; the requirements regarding removal to an interim alternative educational setting and the 45-day time limit do not apply.[8] However, the school system must provide FAPE during the period of suspension or expulsion.[9]

6. Other Dangerous Behavior [20 U.S.C. Sec. 1415(k)(2)]

If school personnel maintain that a child's placement must be changed because of dangerous in-school behavior (other than the weapon and drug cases described above) that is a manifestation of disability[10] and the child's parents dispute the school's decision, the school may seek permission from a due process hearing officer to place the child in an interim alternative educational setting for up to 45 days. The hearing officer may order placement into an interim setting if he or she (1) determines that the school system has demonstrated by more than a preponderance of the evidence that keeping the child in the current placement is substantially likely to result in injury to the child or others; AND (2) considers whether the school system has made reasonable efforts to minimize the risk of harm in the child's current placement, including the use of supplementary aids and services; AND (3) considers the appropriateness of the child's current placement; AND (4) determines that the interim alternative educational setting meets the statutory requirements (see below).

7. Interim Alternative Educational Setting [20 U.S.C. Subsection 1415(k)(2), (3)]

In a weapon or drug case, the interim alternative educational setting is determined by the IEP team, which by definition includes parents.[11] In cases of "dangerous" behavior brought to a hearing officer, the hearing officer makes the determination.[12] In either case, the setting must provide FAPE.[13] It must enable the child to continue to participate in the general curriculum, and to continue to receive the services, including those set out in the child's current IEP, that will enable him or her to meet the IEP goals. Furthermore, the interim alternative educational setting must include services and modifications designed to address the behavior that triggered the child's placement there so that it does not recur.

8. Home Tutoring

Given the statutory requirements for an "interim alternative educational setting," home tutoring will virtually never be a legally permissible placement. Apart from these specific requirements, home tutoring rarely, if ever, can meet the statutory definition of FAPE; thus even children suspended or expelled because their conduct was deemed unrelated to their disabilities ordinarily cannot be placed on homebound instruction.[14] In addition, the U.S. Department of Education's proposed regulations implementing the 1997 IDEA Amendments would require suspended and expelled students to meet the criteria for interim alternative educational settings.[15]

9. Hearings on Discipline Issues and Stay-Put Rights [20 U.S.C. Subsection 1415(j), (k)(6)(A), (k)(7)]

Parents have a right to an expedited impartial due process hearing if they disagree with a determination that a child's behavior was not a manifestation of disability, or with any decision regarding placement.[16] If the child has already been placed in an interim alternative educational setting (for a weapon, drugs or dangerous behavior as described above), he or she must remain there pending the hearing officer's decision (but for no more than 45 days), unless the parent and the state or the school district agree otherwise. All other children retain the right, as under prior law, to "stay-put" in their current educational placement pending resolution of the dispute unless the parent and the state or the school district agree otherwise.

10. Students Not Previously Determined Eligible Under IDEA [20 U.S.C. Sec. 1415(k)(8)]

A student who had not been determined to be eligible for services under IDEA prior to a disciplinary incident may assert IDEA protections if the school system "had knowledge" that he or she was a child with a disability before the behavior in question occurred. The school system will be deemed to have had such knowledge if (1) the parent expressed concern in writing that the child needs special education and related services; OR (2) the child's behavior or performance demonstrates the need for such services; OR (3) the parent has requested an evaluation; OR (4) the child's teacher or other school system personnel has expressed concern about the child's behavior or performance to other school system staff.[17]

If the school district did not "have knowledge," the child can be subjected to the same disciplinary measures to which non-disabled children are subjected. However, if an evaluation is requested it must be expedited, and a free appropriate public education, including special education and related services provided if the child is found to be a child with a disability. Pending the results of the evaluation, the child remains in the "educational placement" determined by school authorities. The statute's use of the phrase educational placement should mean that educational services must be provided during this period, even if the child has been suspended or expelled from school.

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HIGHLIGHTS OF THE DISCIPLINE PROVISIONS OF IDEA '97

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11. Referral to and Action by Law Enforcement and Judicial Authorities [20 U.S.C. Sec. 1415(k)(9)(A)]

The 1997 Amendments state that nothing in IDEA shall be construed to prohibit schools from "reporting a crime committed by a child with a disability to appropriate authorities." The terms "reporting" and "appropriate" authorities are not defined in the statute, and therefore must be given their ordinary meaning. Thus properly interpreted, the new language limits schools to notifying law enforcement agencies (e.g., police) of crimes, and does not authorize notifying the judicial branch, e.g. through the filing of delinquency petitions. In regard to the judiciary, the new law simply provides that nothing in IDEA "shall be construed...to prevent...judicial authorities from exercising their responsibilities with regard to the application of Federal and State law to crimes committed by a child with a disability." The legislative history of these provisions explains that schools may not report crimes to even "appropriate" authorities where doing so would circumvent the school's obligations to the child under IDEA.[18]

12. Transmission of Records When Crimes are Reported [20 U.S.C. Sec. 1415(k)(9)(B)]

IDEA now states that when a school reports a crime alleged to have been committed by a child with a disability, it must send copies of the child's special education and disciplinary records to the "appropriate authorities" to whom it reports the alleged crime. Other provisions of IDEA[19] require states and local school systems to comply with the Family Educational Rights and Privacy Act (FERPA)[20] which, with a few narrow exceptions, prohibits disclosure of education records without prior written parental consent (or the consent of a student aged 18 or older). Therefore, a school may not send records to the authorities to whom it has reported a crime unless the disclosure falls within one of FERPA's very narrow exceptions.[21]

13. Youth Incarcerated in Adult Facilities [20 U.S.C. Subsection 1412(a)(1)(B)(ii), 1414(d)(6)]

IDEA now permits states, if consistent with state law, to deny IDEA instruction and services to youth aged 18 through 21 who are incarcerated in adult facilities and, in their last educational placement prior to adult incarceration, were not identified as being a child with a disability under IDEA and did not have an IEP.[22] The new law also makes exceptions to certain IEP requirements for youth, regardless of age, who are convicted as adults and incarcerated in adult prisons. Students who will not be released from prison before they reach the age limit for receiving services under IDEA may be denied transition planning and transition services. In order to ensure that youth who do actually leave prison before they "age out" of IDEA receive transition services, as Congress intended, (1) children should not be denied transition planning and services until they have exhausted direct appeals of their conviction and sentence, and (2) the release date used to determine whether a youth retains the right to transition planning and services must be the earliest date under state law on which he or she might be released, taking into account all reductions and credits on the child's sentence for which he or she may be eligible.[23]

In addition, the IEP team may modify a youth's IEP or placement notwithstanding the statutory components of an IEP or IDEA's least restrictive environment requirement if the state "has demonstrated a bona fide security or compelling penological interest that cannot otherwise be accommodated." This provision should be construed to permit only individualized determinations regarding bona fide security and compelling penological interests, and to prohibit institutional policies of general application that have the effect of modifying or limiting IEPs. Administrative convenience, lack of funds or need for cost reduction measures, or the promotion of prison discipline or rehabilitation through the withholding of services IDEA otherwise requires should not constitute a "compelling penological interest" for purposes of this provision.

Footnotes

[1] All citations are to the U.S. Code as amended by the IDEA Amendments of 1997, Pub. L. 105-17, 111 Stat 37.

[2] See Judith E. Heumann, Assistant Secretary Office of Special Education and Rehabilitation Services and Thomas Hehir, Director, Office of Special Education Programs, Memorandum to Chief State School Officers Re: Initial Disciplinary Guidance Related to Removal of Children with Disabilities from their Current Educational Placement for Ten School Days or Less, (OSEP 97-7, September 12, 1997) (hereinafter "OSEP Memo"; Notice of Proposed Rulemaking (hereinafter "NPRM"), 62 Federal Register 55025, 55074 (September 22, 2997) (proposed 34 C.F.R. Section 300.121 (c)(2).

[3] See OSEP Memo, supra; NPRM, supra, 62 Fed. Reg. At 55103 (proposed 34 C.F.R. Section 300.523(b)).

[4] See OSEP Memo, supra, NPRM, supra, 62 Fed. Reg. At 55102 (proposed 34 C.F.R. Section 300.520(b), (c)).

[5] "Weapon" means "a weapon, device, instrument, material, or substance, animate or inanimate, that is used for, or is readily capable of, causing death or serious bodily injury, except that such term does not include a pocket knife with a blade of less than 2 inches in length." See 20 U.S.C. Sec. 1415(k)(10)(D), incorporating by reference the definition of "dangerous weapon" found at 18 U.S.C. Sec. 930(g)(2). For definitions of "illegal drugs" and "controlled substance," see 20 U.S.C. Sec. 1415(k)(10)(A).

[6] See 20 U.S.C. Sec. 1415(k)(6)(A)(ii), incorporating by reference the standards set out in 20 U.S.C. Sec. 1415(k)(2).

[7] Id.

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Footnotes (continued)

[8] See 20 U.S.C. Subsection 1415(k)(4)(A), (5)(A).

[9] 20 U.S.C. Sec. 1415(k)(5)(A), incorporating by reference 20 U.S.C. Sec. 1412(a)(1).

[10] If the school determines that the behavior is not a manifestation of disability, the statute school officials to characterize the behavior as a violation of the school discipline code and subject the child to the same disciplinary measures to which non-disabled children are subjected. See 20 U.S.C. Sec. 1415(k)(4)(A), (5)(A). However, the child must continue to receive FAPE. 20 U.S.C. Sec. 1415(k)(5)(A), incorporating by reference 20 U.S.C. Sec. 1412(a)(1).

[11] 20 U.S.C. Sec. 1414(d)(1)(B)(i).

[12] It may be expected, however, that schools will present a specific proposed interim alternative educational setting to the hearing officer. Parents must be permitted to participate in developing any such proposal. See 20 U.S.C. Sec. 1414(f) as amended (local and state educational agencies "shall ensure that parents of each child with a disability are members of any group that makes decisions on the educational placement of their child"). See also 20 U.S.C. Sec. 1414(d)(1)(B)(i) (parents as IEP team members).

[13] 20 U.S.C. Sec. 1412(a)(1).

[14] Under IDEA, "free appropriate public education" means "special education and related services that (A) have been provided at public expense, under public supervision and direction, without charge, (B) meet the standards of the State educational agency, (C) include an appropriate preschool, elementary or secondary education in the State involved, and (D) are provided in conformity with the individualized education program..." 20 U.S.C. Sec. 1402(8). Post- "suspension" or "expulsion" education thus must include "an appropriate elementary or secondary education in the state involved." Education limited to the special education supports (e.g. three hours per week of assistance in math related to a learning disability) and/or related services listed on a child's pre-expulsion IEP does not meet this standard. Homebound instruction, particularly the time- and subject matter-limited variety routinely provided in many school systems, will rarely meet this standard either.

In addition, most states and many local school systems have adopted minimum requirements regarding the length of the school day, the content of curricula and the amount of time during the day that must be devoted to academic instruction. These requirements define in part "an appropriate elementary or secondary education in the state involved," 20 U.S.C. Sec. 1402(8)(C), and (to the extent adopted or approved by the state) are "standards of the State educational agency" that must be met pursuant to 20 U.S.C. Sec. 1402(8)(B). Home tutoring may be challenged as failing to provide a "free appropriate public education" on these bases as well.

[15] NPRM, supra, 62 Fed. Reg. at 55074 (proposed 34 C.F.R. Sec. _00.121(c)(3), incorporating by reference proposed 34 C.F.R. Sec. 300.522).

[16] Under the U.S. Department of Education's proposed regulations, expedited hearings must result in a decision within 10 business days of the hearing request, unless the parents and school officials agree otherwise. See NPRM, supra, 62 Fed. Reg. at 55104 (proposed regulation 34 C.F.R. Sec. 300.528(a)(1).

[17] A parent need not have expressed concern about special education needs in writing if "the parent is illiterate or has a disability that prevents compliance with [these] requirements." 20 U.S.C. Sec. 1415(k)(8)(B)(i).

[18] See statement of Sen. Harkin, one of the legislation's co-sponsors, at Cong. Rec. May 14, 1997 at S4403 ("The bill also authorizes...proper referrals to police and appropriate authorities when disabled children commit crimes, so long as the referrals, do not circumvent the school's responsibilities under IDEA").

[19] Specifically, 20 U.S.C. Subsec. 1412(a)(8) and 1417 (c).

[20] 20 U.S.C. Sec. 1232g.

[21] For FERPA exceptions, see 20 U.S.C. Sec. 1232g(b); 34 C.F.R. Sec. 99.31; 34 C.F.R. Sec. 99.38 as added to the FERPA regulations by 61 Fed. Reg. 59297 (November 21, 1996). There is no blanket exception for crime reports.

[22] The statute is somewhat confusing on this point, stating that FAPE may be denied if, in the placement prior to incarceration, the student was not identified as a child with a disability "or"' did not have an IEP. The Senate Committee Report on the 1997 IDEA amendments, however, clearly states that, under this new provision, youth "who did not have an IEP in their last educational placement but who had actually been identified should not be excluded from services." Senate Report 105-17 at 11. The U.S. Department of Education's proposed regulations reflect this view, and require services for any youth who was identified in the immediately prior placement, even if he or she did not have an IEP. See NPRM, supra, 62 Fed. Reg. At 55074-75 (proposed regulation 34 C.F.R. Sec. 300.122(a)(2)).

[23] The U.S. Department of Education's proposed regulation states that transition planning and services requirements do not apply to students whose IDEA eligibility will end, because of their age, "[b]efore they will be eligible to be released from prison based on consideration of their sentence and eligibility for early release." 62 Fed. Reg. At 55087 (proposed 34 C.F.R. Sec. 300.311(b)(2)).

The following memorandum regarding the discipline provisions of IDEA '97 was reprinted with permission from the U.S. Department of Education, Office of Special Education and Rehabilitative Services.

MEMORANDUM

To: Chief State School Officers

From: Judith E. Heumann, Assistant Secretary, *OSERS*
Thomas Hehir, Director, *OSEP*

Subject: Initial Disciplinary Guidance Related to Removal of Children with Disabilities from the Current Educational Placement for Ten School Days or Less

The purpose of this memorandum is to provide initial guidance on the requirements of the Individuals with Disabilities Education Act Amendments of 1997 (IDEA '97) as they relate to the removal of children with disabilities from their current educational placement for ten school days or less. The Department of Education has received numerous requests for guidance concerning the discipline provisions of IDEA '97. The Department plans to regulate in each of the areas where clarification is needed.

Four basic themes run throughout the statute concerning discipline:

(1) All children, including children with disabilities, deserve safe, well-disciplined schools and orderly learning environments;

(2) Teachers and school administrators should have the tools they need to assist them in preventing misconduct and discipline problems and to address these problems, if they arise;

(3) There must be a balanced approach to the issue of discipline of children with disabilities that reflects the need for orderly and safe schools and the need to protect the right of children with disabilities to a free appropriate public education (FAPE); and

(4) Appropriately developed IEPs with well developed behavior intervention strategies decrease school discipline problems.

With regard to discipline for children with disabilities, IDEA '97:

- Brings together for the first time in the statute the rules that apply to children with disabilities who are subject to disciplinary action and clarifies for school personnel, parents, students, and others how school disciplinary rules and the obligation to provide FAPE fit together by providing specificity about important issues such as whether educational services can cease for a disabled child; how manifestation determinations are made; what happens to a child with disabilities during parent appeals; and how to treat children not previously identified as disabled.
- Includes the regular education teacher of a child with a disability in the child's IEP meetings to help ensure that the child receives appropriate accommodations and supports within the regular education classroom, and gives the regular teacher an opportunity to better understand the child's needs and what will be necessary to meet those needs, thus decreasing the likelihood of disciplinary problems.
- Allows school personnel to move a student with disabilities to an interim alternative educational setting for up to 45 days, if that student has brought a weapon to school or a school function, or knowingly possesses or uses illegal drugs or sells or solicits the sale of a controlled substance while at school or a school function.
- Gives school personnel the option of asking a hearing officer to move children with disabilities to an interim alternative educational setting for up to 45 days if they are substantially likely to injure themselves or others in their current placement.

INITIAL GUIDANCE REGARDING REMOVAL OF CHILDREN WITH DISABILITIES FROM THEIR CURRENT PLACEMENT

We recognize that the statute is susceptible to a number of interpretations in some areas related to discipline, but the position enunciated below represents what we believe is the better reading of the statute. We are providing this information (in a question and answer format) to assist States and school districts in implementing IDEA '97 prior to publication of Department regulations. To the extent these questions and answers provide information not specifically addressed in the Statute, the information is being provided as non-binding/non- regulatory guidance. We will be issuing proposed regulations in the near future that reflect the positions taken in this document.

QUESTION 1: Under IDEA, do public agencies have a responsibility, as part of the IEP process, to consider a child's behavior?

ANSWER: Yes. Section 614(d)(2)(B) requires the IEP team "in the case of a child whose behavior impedes his or her learning or that of others, [to] consider, when appropriate, strategies, including positive behavioral interventions, strategies, and supports to address that behavior." In addition, school districts should take prompt steps to address misconduct when it first appears. Such steps could, in many instances, eliminate the need to take more drastic measures. These measures also could be facilitated through the individualized education program (IEP) and placement processes

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U.S. Dept. of Education Memorandum on Disciplinary Guidance Under IDEA '97

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required by IDEA. For example, when misconduct appears, a functional behavioral assessment could be conducted, and determinations could be made as to whether the student's current program is appropriate and whether the student could benefit from the provision of more specialized instructional and/or related services, such as counseling, psychological services, or social-work services in schools. In addition, training of the teacher in effective use of conflict management and/or behavior management strategies also could be extremely effective. In-service training for all personnel who work with the student and, when appropriate, other students, also can be essential in ensuring the successful implementation of the above interventions.

QUESTION 2: Does the right to a free appropriate public education extend to children with disabilities who are suspended or expelled?

ANSWER: Yes. A free appropriate public education must be made available to all eligible children with disabilities, including children with disabilities who have been suspended or expelled from school. (Section 612(a)(1)).

QUESTION 3: What is the meaning of the phrase "children with disabilities who have been suspended or expelled from school?"

ANSWER: The Department believes that the phrase means children with disabilities who have been removed from their current educational placement for more than ten school days in a given school year.

QUESTION 4: Must educational services be continued during the removal of a child with a disability from his or her educational placement for ten school days or less?

ANSWER: No. The Department does not believe that it was the intent of Congress to require that FAPE be provided when a child is removed for ten school days or less during a given school year. However, there is nothing in the IDEA '97 that would prevent the provision of FAPE during this time.

QUESTION 5: Must there be a manifestation determination before a student with disabilities can be removed from his or her current education placement for a period of ten school days or less during a given school year?

ANSWER: No. The Department does not believe that the statute requires a manifestation determination prior to a removal for a period of ten school days or less in a given school year. However, if an action that involves the removal of a child with a disability from his or her current educational placement for more than ten school days in a given school year is contemplated, the Department believes that a manifestation determination should be required and the manifestation determination must take place as soon as possible but in no case later than ten school days after the decision to take that action is made. (615(k)(4)(A)).

QUESTIONS 6: Must a functional behavioral assessment be conducted prior to a removal of ten school days or less during a given school year?

ANSWER: No. The Department does not believe the statute requires a functional behavioral assessment, if a child with a disability is removed from his or her current educational placement for ten school days or less in a given school year, and no further disciplinary action is contemplated.

QUESTION 7: Are there any specific actions that a school district is required to take during a removal of a child with a disability from his or her educational placement for ten school days or less?

ANSWER: If no further removal is contemplated, the Department does not believe that other specific actions are required during this time period. However, school districts are strongly encouraged to review as soon as possible the circumstances that lead to the child's removal and consider whether the child was being provided services in accordance with the IEP and whether the behavior could be addressed through minor classroom or program adjustments, or whether the IEP team should be reconvened to address possible changes to the IEP.

QUESTION 8: Does IDEA continue to allow a school district to seek a court order to remove a student with a disability from school or otherwise change the student's placement? If so, under what circumstances?

ANSWER: Yes. IDEA continues to allow a school district to seek to obtain a court order to remove any student with a disability from school or to change the student's current educational placement if the school district believes that maintaining the student in the current educational placement is substantially likely to result in injury to the student or to others.[1]

In addition, the new statute allows school authorities to ask a hearing officer to move children with disabilities to an interim alternative educational setting for up to 45 days if they are substantially likely to injure themselves or others in their current placement. The hearing officer may move the child to an alternative educational setting if the public agency demonstrates by evidence that is more than a preponderance of the evidence that maintaining the child in the child's current placement is substantially likely to result in injury to the child or others. The hearing officer must consider the appropriateness of the child's placement, whether the school district has made reasonable efforts to minimize the risk of harm in the child's current placement, including the use of supplementary aids and services, and determine that the interim alternative educational setting meets the requirements of Section 615(k)(3) of the Act.

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[1] *Honig v. Doe*, 108 S. Ct. 592, 606 (1988).

The following is a response letter to the OSERS/ OSEP disciplinary guidance memo (pages 28-29 of this Newsletter). A list of the authors of the letter appears at the end of the article.

Letter to Chief State School Officers:

We write on behalf of the National Down Syndrome Congress, the Autism National Committee, TASH, and many parents from around the country who participated in the legislative conversations conducted by David Hoppe, Trent Lott's Chief of Staff, which formulated the new Act. We write to address the U.S. Department of Education's letter sent to you on September 19, 1997 over the signatures of the Assistant Secretary and Director.

First, we wish to call to your attention two new provisions of the Act, in Section 607, which render the recent letter advisory at best, and which set high standards for any regulation that may later be issued by the Department.

"Any written response by the Secretary . . .regarding a policy, question or interpretation under Part B of this Act shall include an explanation that the written response -

(1) Is provided as informal guidance and is not legally binding;

"The Secretary may not implement, or publish in final form any regulation that would procedurally or substantively lessen the protections provided to children under this Act, as embodied in regulations in effect on July 20, 1983 . . ., except to the extent that such regulation reflects the clear and unequivocal intent of the Congress in Legislation."

Second, we believe that several of the positions preliminarily articulated in the September 19, 1997 letter are wrong.

The language of the Act is plain and clear. At Sec. 612(a)(1) the Act says:

"A free appropriate public education [shall be] available to all children with disabilities, residing in the State between the ages of 3 and 21, inclusive, **including children with disabilities who have been suspended or expelled from school.**"

At Sec. 615(k), the Act expressly applies this command to any and every disciplinary action which is authorized by the Act:

"(5)(A) In General. If the result of the review described in paragraph (4) is . . . the behavior of a child with a disability was not a manifestation of the child's disability, the relevant disciplinary procedures applicable to children without disabilities may be applied to the child in the same manner in which they would be applied to children without disabilities, **except as provided in section 612 (a)(1).**"

The referenced paragraph (4) covers "a disciplinary action . . . contemplated as described in paragraph 1. . ." It is this referenced paragraph 1 which authorizes disciplinary actions "for not more 10 school days (to the extent such alternatives would be applied to children without disabilities)."

Such clearly expressed Statutory language cannot be evaded, but rather must be "enforced by the Courts" and by rulemaking agencies. West Virginia Hospitals, Inc. v. Casey, 499 U. S. 83, 100 (1991) (Justice Scalia); Negansott v. Samuels. 507 U.S. 99, 104 (1993); Iselin v. United States, 270 U.S. 245, 250-51 (Justice Brandeis).

As a result, "appropriate public education" must continue even during any suspension.

In effect, the Act has adopted as law the practice of in-school suspension that must be consistent with FAPE. As you know, this practice has taken strong hold in recent decades in many schools. Among the bases of this increasingly widespread practice of "in-school suspension" — now made mandatory for all children with disabilities — is the professional wisdom that while discipline is being exerted, a child's connection with the school and with teaching and learning should not be broken and to do so actually rewards children the school intends to punish. School children should not be put on the street. In the suburbs and everywhere, parents now are usually working outside of the home.

The history of the new Act, also made the Act's intentions clear. The Chairman of the Senate Committee said that all the disciplinary actions allowed under the Act are get forth in the Act itself and clearly indicated what schools can and cannot do:

"This bill brings together, for the first time, in the statute the rules that apply to children with disabilities who are subject to disciplinary action and clarifies for school personnel, parents, and others how school disciplinary rules and the obligation to provide a free, appropriate education fit together. The bill provides specificity about important issues such as whether educational services can cease for a disabled child — they cannot — how manifestation determinations are made, what happens to a child with disabilities during the parent appeals, and how to treat children not previously identified as disabled." 143 Congressional Record No. 62, page S4359, col.2. (May 13, 1997)

Closing floor debate on an Amendment which would have reversed those intentions, the ranking minority sponsor was clear and concrete about what the Act requires -- including for disabled students no out-of-school suspensions:

"My colleague also quotes a parent of a nondisabled child who was told by a lawyer that she has no rights when her child's class is disrupted by a disabled child. I say to that parent she better get a new lawyer."

"They have a right to a class environment that is safe and conducive to learning."

"That parent has a right to insist that the schools develop positive behavior approaches and train teachers and provide them with the necessary supports. What they don't have is the right to kick that disabled kid out of the class just as school systems cannot kick out African-American children when a white child or his parents are uncomfortable around African-Americans."

"Can we have school environments that are safe and conducive to learning without kicking disabled kids out? Yes we can. Just ask Dr. Mike McTaggart of West Middle School in Sioux City, IA. In just one year, the number of suspensions of nondisabled children went from 692 to 156, of which 7 were out-of-school suspensions. The number of suspensions of disabled children went from 220 to zero. Attendance has gone from 72 percent to 98.5 percent. Juvenile court referrals went from 267 to 3."

"His philosophy of discipline for all

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Letter to Chief State School Officers:

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students is to use discipline as a tool to teach rather than [only] to punish."

"In closing, let's reject the Gorton amendment and send a message that we can ensure school environments that are safe and conducive to learning without gutting the rights and protections of disabled children." 143 Congressional Record, No. 62 page S4403, col. 3 (May 14, 1997)

The central consideration in the clear statutory language about discipline is that articulated by Senator Harkin: "to insist that schools develop positive behavioral approaches and train teachers and provide them with the necessary supports. . . ." (May 14, 19-97)

Rather than subjecting disabled children to ten day out of school suspensions, in violation both of the Act and of sound professional practice, we urge you to prepare and support your schools -- as the Act requires — to "acquire and disseminate. . . and [to] adopt promising educational practices. . . ." 20 U. S. C. Section 1413(a)(3)(B) and, effective July 1, 1998, Section 612 (a)(14). The state of the art in the effective education of disabled children whatever their disabilities and the knowledge of what works in classroom management [cite, for example Kerr & Nelson, and Hill Brown's books] far exceeds what many schools now know and do -- as the Act's history and its findings show the Congress knew and wished to change.

Quite simply, in its carefully written and integrated provisions this Act requires that problems of student behavior, ultimately and in anticipatory fashion, be resolved and avoided by using best educational practices and strengthening their education. Punishment is provided for, but circumscribed by the Act's plain limitations, not by putting children out of school and breaking their connection to education.

We hope you will proceed in accordance with the Act, and both encourage and enable those schools for which you have responsibility to do so, by adhering to the Act's notations on the kinds of discipline that may be used and – affirmatively — by aggressively assisting those schools to know and to adopt both the best educational practices and the best classroom management practices.

We ask you also to inform the responsible officials of the U.S. Department of Education that you count it no favor so cavalierly to advise the states to proceed in a manner contrary to the directions of the Act.

Thomas K. Gilhool Esq., Judith A. Gran, Esq., Frank Laski, Esq., Barbara Ransom, Esq.
Public Interest Law Center of Philadelphia
Philadelphia, PA

Kathleen Boundy, Esq., Eileen Ordover, Esq.
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Monahan & Cohen, Chicago, IL

Evaluations, Eligibility, IEPs & Placements

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is paid for by the state, and is confidential (discussions may not be used in evidence in hearings or trials).

ENFORCEMENT OF RIGHTS

Sec. 615 retains two important rights-enforcement provisions, but it also makes significant changes in rights-enforcement, particularly with respect to discipline and attorney fees.

Sovereign immunity abrogated. The state still may not defend against a suit on the basis that the state has sovereign immunity, for IDEA still abrogates the state's immunity.

ADA, Sec. 504, Sec. 1983, and other rights enforcement. The student and parents, after exhausting their IDEA administrative remedies, still may sue under other federal rights-granting statutes, particularly the federal constitution (for due process or equal protection violations), Americans with Disabilities Act, Sec. 504 of the Rehabilitation Act, and "other federal laws" (including, presumably, Sec. 1983 of the Civil Rights Act).

Attorney fees. As to attorney fees, although IDEA continues to make them available to parents if they prevail against a local or state agency, it restricts parents' rights of recovery in important procedural and substantive ways.

Amount of fees. A court may award reasonable attorney fees. The "reasonable" limitation is not new and still requires the court to base the fees on the rates prevailing in the community in which the case arose for the kind and quality of the services furnished; no bonus or multiplier may be used to calculate the fees. In addition, the court may reduce the attorney fees if the parent unreasonably protracted the final resolution of the controversy, if the fees unreasonably exceed the community rate, or if the parent's attorney did not provide the agency the information to which it is entitled (notice about nature of dispute and proposed resolution).

Likewise, the parent is still required to accept a reasonable offer of settlement or risk losing the fee recovery; and the parent will lose the recovery if the administrative hearing officer or judge finds that the relief that the parent finally obtains is not more favorable than the offer or that the parent, having prevailed, was not substantially justified in rejecting the settlement offer.

IEP excluded. In a new and limiting provision, however, Sec. 615 prohibits attorney fees recovery if the attorney's services related to any meeting of the IEP team; however, the attorney's services were at an IEP meeting convened as a result of an administrative proceeding judicial action, or, in the state's discretion, for mediation and if the parent prevails, the parent may recover the fees related to that meeting.

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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NOVEMBER/DECEMBER 1997

Newsletter

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DON'T FORGET!

Upcoming Annual TASH Conference Dates

Many of you have requested information about future dates and sites for the Annual TASH Conference. We've provided a list of the conference dates for the next three years for which we have already negotiated and contracted space. There have been numerous suggestions from members to return the dates of the conference to November. We are currently negotiating sites for 2001, 2002, and 2003. In doing so, we will make every effort to secure dates in November, or at the latest the first week in December. The current state of the travel, meeting, and tourism industry makes it increasingly difficult to negotiate reasonable convention rates. We must consider site availability, preferred dates, and lowest available cost to meet the needs of our diverse membership. Thank you for your input. Please feel free to contact me with any further suggestions or comments regarding the Annual TASH Conference.

Denise Marshall, Director of Training and Technical Assistance
410-828-8274 x103 • dmarsh@tash.org

1998
Location: Seattle, Washington
Dates: December 2, 1998 - Pre-Conference Workshops and Opening Reception
December 3-5, 1998 – Annual TASH Conference
Site: Seattle Sheraton Hotel and Towers; and the Washington State Convention Center

1999
Location: Chicago, Illinois
Dates: December 8, 1998 - Pre-Conference Workshops and Opening Reception
December 9-11, 1998 – Annual TASH Conference
Site: Chicago Hilton & Towers

2000
Location: Miami, Florida
Dates: December 6, 2000 - Pre-Conference Workshops and Opening Reception
December 7-9, 2000 – Annual TASH Conference
Site: The Fontainbleau Hilton Resort and Towers

The California Chapter of The Association for Persons with Severe Disabilities (Cal-TASH)

announces its

16th Annual Conference

Capitol Connections: Stories and Successes • March 26-28, 1998

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This conference brings together parents, consumers, teachers, administrators, communication specialists, and others interested in providing support to individuals with significant disabilities. Each year the conference has grown to the enrollment last year of over 600.

For more information or to register, please write or call: The Cal-TASH Conference, 6219 Avenida Gorrion, Goleta, CA 93117
(Phone) 805-967-2042 • (Fax) 805-683-2482

Update on TASH's Interest & Action (I&A) Groups

EARLY CHILDHOOD INTEREST & ACTION GROUP

Beth Brennan and Elizabeth Erwin will continue to be co-coordinators for this I&A Group. The co-chairs hosted an I&A Group meeting during the '97 Annual Conference that was highly interactive and included Pip Campbell, Kat Stremmel, Alan Berger, and others.

Among the issues identified for further dialogue and focus:

- including those who provide supports for young children to enable them to be included in their natural environments
- community preschools
- playgrounds
- Head Start programs

The Early Childhood I&A Group identified the following action goal for 1998: To develop a position statement that encompasses the ethical and practical considerations surrounding issues specific to providing supported opportunities for very young children with significant disabilities and their families to be involved in their natural environments. Additionally, the I&A Group hopes to incorporate that position statement in a compilation of newly written or previously published articles that would provide families and other interested individuals with a starting base of early childhood information for those ethical and practical considerations.

For more information or to participate in the group, contact:
Beth Brennan, e-mail: bbrennan@sfsu.edu or Elizabeth Erwin, 201-744-3975

FAMILY ISSUES INTEREST & ACTION GROUP

Issues of criticality for this Interest & Action Group have been identified as

- helping families understand new dimensions of IDEA (particularly accessing general education curriculum); and
- including families with very young children

The Family I&A Group plans to focus on establishing more effective communication links with families (utilizing the TASH *Newsletter*; the TASH web site; Partners in Policymaking and Parent Training Center networks, etc.) and recruiting family members to attend the 1998 TASH conference and participate in TASH's social justice efforts.

For more information or to participate in the group, contact:
Barb Buswell, Coordinator, 719-531-9400

LEISURE AND RECREATION INTEREST & ACTION GROUP

Cindy Burkhour, Coordinator of the Leisure and Recreation I&A Group, reports that the Group was very active as the TASH representative on the Play Facilities Regulatory Negotiation Committee of the Access Board. The Committee was responsible for developing the ADA accessibility design guidelines for play facilities.

In representing TASH, the Leisure and Recreation I&A Group brought forward the following concepts and issues (this is a partial list)

- ALL play facilities will provide maximum choice of playthings
- ALL play facilities will provide social play interaction with those on the play structure
- ALL play facilities will provide full integration of accessible play opportunities throughout the play facilities.
- ALL play facilities will provide opportunity for use by children who have a variety of abilities
- ALL play facilities will provide access for adults with disabilities to provide support

The Leisure & Recreation I&A Group will continue working on the following critical issues in the upcoming year: inclusion strategies for access to recreation; recreation as a related service under IDEA; continue discussions on integration in sports; and access to extracurricula activities.

For more information or to participate in the group, contact:
Cindy Burkhour, Coordinator, 616-669-9109

Look for updates in the next TASH Newsletter on current work and initiatives by the Multicultural, Paraeducator, and Special Needs Interest & Action Groups!

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105 or e-mail: info@tash.org

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and

~

Promoting excellence in services.

FROM THE EXECUTIVE DIRECTOR

BY NANCY WEISS

With all of the excitement around the annual conference we sometimes overlook the fact that the conference is also the time of TASH's annual meeting. The TASH Executive Board met twice during the conference, on Tuesday afternoon and again on Saturday. Saturday's meeting opened with a business meeting and open forum. Accomplishments of note during the December Executive Board meetings included:

- Election of Officers: The new slate of officers is as follows: Liz Healey, President; Mark Partin, Vice-President; Mike Auberger, Treasurer; Joe Wykowski, Secretary; and Doug Biklen, Chair of the Executive Committee.

  Board Membership: David Belton resigned from the Board in November. Tim Knoster was the nominee from the previous election who had the next highest number of votes. Tim has filled David's vacancy on the Board.

- TASH's Structure: The Board discussed the structure that has been in place for two years and agreed that the structure was cumbersome and seemed to make it more difficult for members to participate in committee activities. We are going back to the structure that TASH members are familiar with - Operating Committees and Interest and Action Groups (or, what we used to call committees), which will continue to operate as they always have. We will do away with the added level of "Open Project Groups."

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WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext 104, e-mail:mroth@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions or advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

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- Dues Increase: The Board reviewed the dues structure. National dues have not been increased since 1990. The Board agreed that it did not want to increase dues for self-advocates, family members, students, or other "reduced fee" members. Dues for General (professional) members and the rate for family-group rate members will be increased by $3. The rate for agencies (which includes universities, schools, and libraries) will be increased by $10. The Membership Operating Committee is studying whether the cost for foreign members should be increased to reflect TASH's actual mailing costs.

- Future Conference Sites: It is nearing the time to schedule conference sites for the years 2001, 2002 and 2003. We are scheduled for Seattle in 1998 (December 2-5), Chicago in 1999 (December 8-11), and Miami in 2000 (December 6-9). Members of the new Nevada TASH Chapter came to the Board meeting to urge consideration of Las Vegas as a conference site. The cities being considered for 2001 are San Francisco, Los Angeles and Las Vegas. For the 2002 conference, the cities under consideration are Boston and Chicago, and in 2003, Orlando is being considered. An effort will be made to hold all future conferences the week just before, or just after, Thanksgiving.

- Blueprint for Action: The Board "brainstormed" on the development of a list of priorities and an action plan. This list is being reviewed by the Board now and will be finalized over the next month or two. The draft priorities are as follows:

  - *Priorities: Strengthen the organization and improve fiscal stability.* Specific actions to include focusing on diversity, continuing to improve finances, building membership, and supporting and strengthening chapters and committees.

  - *Main focus issues should be:*

Education – emphasis on IDEA
Community Living – emphasis on MiCASA, Home of Your Own and Closing Institutions
Human Rights- emphasis on Assisted Suicide and abolishing the use of aversives

  - *How to Accomplish Priorities:*

— Strengthen options for electronic communication. For example, set up list servs, establish better web page links with chapters and other organizations, and use our web site to more effectively promote knowledge of TASH, its values, and the benefits of membership
— Promote a strong message about who we are by marketing TASH's identity through the use of public relations initiatives, press releases, and broader and more regular dissemination of information
— Improve internal communication (Board to staff, staff to Board, staff to chapters, chapters to staff, etc.)
— Strengthen focus on abolishing the use of aversive procedures through the activities of the Positive Approaches Interest and Action Group
— Conduct more regional workshops
— Strengthen alliance with SABE (Self Advocates Becoming Empowered) and include more self-advocates in all TASH activities
— Strengthen outreach efforts to other social justice groups
— Establish three new internal Board committees: Finance, Personnel and Development

- Alliance with SAFE: At the Board meeting, the SAFE National Board made a proposal which would merge SAFE's national organization with TASH. TASH would carry forward some of the goals and activities that SAFE had prioritized. The details of this merger are being worked on by the two Boards.

- Resolutions: The Board is working on updating TASH's resolutions. A new resolution on Physician Assisted Suicide was adopted.

- 1998 Activities: Staff updated the Board on two new activities for 1998. TASH will collaborate with the Robert Wood Johnson Self-Determination Project to organize a National Conference on Self-Determination and Community Living (to be held July 9-11 at the Minneapolis Hilton and Towers). TASH will also produce a quarterly newsletter on self-determination. Both of these activities are funded by the Robert Wood Johnson Foundation.

- 1998 Newsletter Topics: *Newsletter* topics suggested for this year include: MiCasa; Institutional Closure, and Home/Health Attendant Care; International and Multi-cultural issues; Human Rights and the Abolishment of the Use of Aversive Procedures; Leisure/Recreation; Assistive Technology; Criminal Justice/Civil Rights; and Advocacy, Grassroots Organizing, Labeling, Language Use and the Media.

- Operating Committee Reports:

Publications: The Publications Operating Committee is working on identifying the next JASH editor. JASH and the *Newsletter* published a call for nominations. A search committee will be formed to make a recommendation to the Board. Additionally, the Publications Operating Committee proposed a new policy on advertising, publishing, exhibiting, reprinting material and rental of mailing lists. This committee also is working on a catalog of publications to be sold through TASH and proposed the establishment of a new journal which will be available via the Internet.

Membership: The Membership Operating Committee is working on a member needs survey and a direct mail membership campaign for the Summer. It was suggested that TASH work on a joint membership program with SABE.

Chapter: The Chapter Operating Committee held its first Chapter Leadership Training Day at the 1997 conference. It was very successful and a similar session is being planned for the 1998 conference. The priority for the Chapter Operating Committee is to maximize electronic networking capacity.

Governmental Affairs: The Governmental Affairs Operating Committee elected Mike Auberger as its Chair. The recommendation of this committee is to focus on IDEA and MiCASA. Efforts will be made to make materials about IDEA and MiCASA accessible to all TASH constituencies. Additional areas of focus include: effecting people-friendly election outcomes, strengthening the voice of grassroots advocates, increasing our visibility in Washington, D.C., and building alliances with other like-minded national groups.

ILLINOIS CHAPTER

The 1998 Annual State Conference of Illinois-TASH, "Strategies for Building Supports, for All," will be February 24 and 25, 1998 at the Hyatt Regency Hotel, Oak Brook, Illinois.

Pre-conference workshops will take place on February 23. To make hotel reservation, contact the Hyatt Regency directly at 630-573-1234 or 1-800-233-1234 (tell them you're with the IL-TASH conference to receive conference rates).

For more information or to register for the conference, contact Mark Doyle at Everyone Is Welcome, 630-584-0970 or e-mail EIWelcome@aol.com

INDIANA CHAPTER

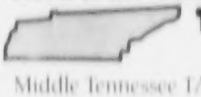
The Indiana Chapter of TASH is planning a one-day workshop in March featuring Dr. Lou Brown. Lou's keynote presentation is entitled "Real Work in the Real World."

The workshop is scheduled for Friday, March 20, 1998 at Connor Prairie in Fishers, Indiana.

In the afternoon, participants will have an opportunity to take part in a series of mini-sessions focusing on important aspects of an individual's life that contribute to success and personal satisfaction in the "real world": Community Living; Public Education (Ages 18-21); High School Inclusion; and Leisure and Social Life.

For more information on this exciting one-day conference, contact Michelle Persinger at 317-255-2564 or Dianna Williams at 812-832-7698.

MIDDLE TENNESSEE TASH



Linda Messamore, Middle Tennessee TASH Chapter President, reports the Chapter is concentrating on reorganizing and revitalizing itself to encompass the entire state rather than just the Middle Tennessee area.

Middle Tennessee

- maintains a Speakers Bureau;
- provides individual and family advocacy; and

TASH CHAPTER

News & Views

- works with local coalitions to increase its membership and the effectiveness of its work.

The Chapter publishes a column in their Coalition newsletter. Middle Tennessee TASH serves members by providing conference stipends and information/referral services. Most recently, the Chapter has been focusing on supporting People First, Tennessee's disability coalition effort, to move people with disabilities from state institutions into the community.

Middle Tennessee TASH also works to support the inclusion of children with disabilities in their local public schools. Other officers of the Middle Tennessee Chapter include Dara Howe, Vice President; Donna DeSteFano, Secretary; and Errol Elshtain, Treasurer.

If you would like to contact Linda Messamore, please call 615-662-0431 (home) or 615-353-2008 (fax).

We wish Middle Tennessee TASH good luck with its reorganization efforts!

MISSOURI TASH

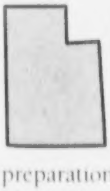
As a result of a Board Retreat last year, the Missouri TASH Chapter developed Mission and Vision Statements, as well as four goal areas. The four goal areas are:

1. Increase membership by 50% by July 1999;
2. Develop a leadership development plan by July 1998;
3. Influence policy decisions by developing and disseminating information/technical assistance for specific critical issues to be identified on an annual basis, and
4. Increase participation of individuals with developmental disabilities in community life.

Kris Weingaertner-Hartke, Chapter President, reports that Missouri TASH activities include submitting information to individual legislators, letter writing campaigns and providing support to local TASH members. Missouri TASH has recently focused on a formal alliance with other organizations to stress the importance of pay equity for community providers.

Missouri TASH produces a newsletter and utilizes a display board at a variety of conferences. The Chapter also gives out stipends to consumers and parents to attend conferences. The 12th Annual Missouri TASH conference will take place on February 20, 1998 at the Henry VIII Hotel in St. Louis. The featured speaker, David Hingsburger will address sexuality and disabilities. Mr. Hingsburger was a keynote presenter at the 1997 TASH National Conference in Boston.

Other Chapter officers include Jean-Paul Bovee, Vice President; Peter Griggs, Secretary; and Peg Capo, Treasurer. For more information you can contact Kris Weingaertner-Hartke at 314-569-8454.



UTAH TASH

The Utah TASH Chapter is currently focusing on parent support, student involvement and personnel preparation as their critical issues. Martin Agran, Chapter President, informs us that dissemination of information to members and other interested persons is their primary activity. Utah TASH hopes to further enhance their support and involvement with state conferences.

Other Utah TASH Chapter officers include Richard Kiefer-O'Donnell, Vice-President and Tim McConnell, Treasurer.

Martin Agran can be reached at Utah State University, Department of Special Education and Rehabilitation, 2865 University Blvd., Logan, Utah 84322-2865.

1997 TASH Conference

The 1997 TASH Conference, We the People, *All* the People, was a huge success and contained many memorable, meaningful, and inspirational moments! We had 2,462 registrants – which is the highest number of attendees since 1990!

Many participants responded that the conference has been getting stronger, better, and more well-rounded each year. We had over 500 sessions which were found to be useful, interesting, and offered a wide variety of information.

The 1998 Call for Presentations is located in this issue of the *Newsletter* on pages 25-28. We hope you will submit a presentation for inclusion at this year's conference. If you are not able to present in Seattle, please pass the form on to someone who may be interested! As you may know, the schedule of sessions offered largely depends on the quality and diversity of individual proposals sent into the central office. We're counting on you to continue to keep the information current, valuable, and useful.

Here are some of the suggested areas of improvement or growth for future conferences noted by 1997 attendees:

- A plan to have more staff or volunteers around to help folks decide on sessions, locate rooms each day of the conference, and assist presenters to assure they have what is needed
- Continue to find ways to improve the conference program so that things are cross-referenced and easy to find for all
- Strengthen the use of alternate formats for all presentations to make them accessible to a wider variety of attendees
- Strengthen the number and variety of sessions in the following areas:
    - — Research
    - — Employment
    - — How disability issues fit within the larger context of social and economic justice, peace, and non-violence
    - — The idea of "invisible supports" – those who support people should be so in tune with those they support to the point that they are invisible to others as a paid worker
    - — The merging of "special" and "general" education - where all students have an individualized education and career plan
    - — Hands-on ideas for adaptations
    - — Functional curriculums
    - — More on how – less on why
- Communicate to presenters that not showing up for a session, or canceling a session due to low numbers of attendees, is frustrating to attendees and does not reflect well on them or the conference as a whole

An event of this magnitude could not be pulled off successfully without hard work and dedication from everyone involved. Thanks to all of you who made this conference such a tremendous success. I look forward to working with the membership, the 1998 Conference Committee, the 1998 Local Committee, In-focus Strand Coordinators, TASH Chapters, TASH Interest and Action Groups, and the TASH central office staff to convene a successful 1998 Annual Conference. Anyone with suggestions, ideas, or wishing to be part of the planning committee should contact me: Denise Marshall, TASH, 29 W. Susquehanna Ave, Suite 210, Baltimore, MD 21204; 410-828-8274x103; dmarsh@tash.org.

In the meantime, take a few minutes over the next several pages to re-visit the exciting sessions and people you encountered during the Boston conference. See you in Seattle!

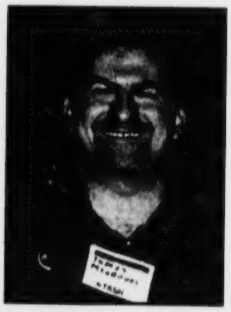
1997 Conference HIGHLIGHTS

With almost 2,500 Attendees

and over 500 sessions...

this was one of the biggest TASH Conferences ever!

Students from the O'Hearn School (above and to the right) provided wonderful entertainment...



...and we all shared touching moments with old and new friends.

Nkosi Asante (pictured left, holding microphone) and members of the New African Voices Alliance offered a stirring tribute to the life and work of Shafik Asante, a scheduled keynote presenter at the '97 conference who passed away in September.

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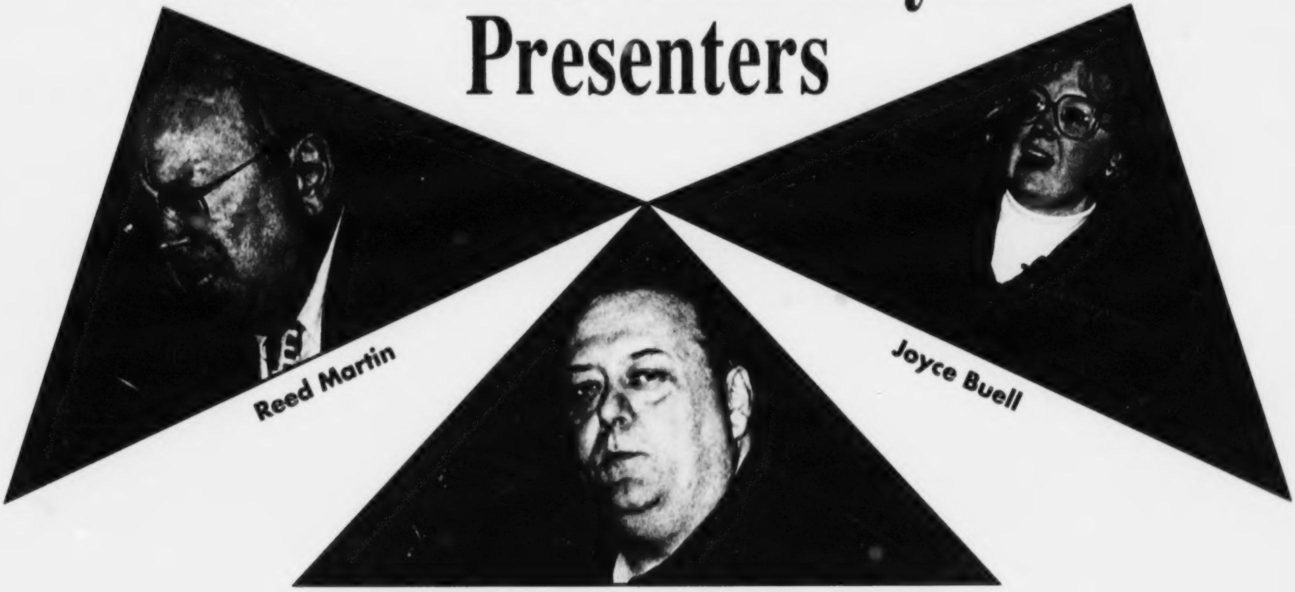
1997 Conference Keynote Presenters



David Hingsburger

1997 TASH AWARDS

Alice H. Hayden Award

Elizabeth Brennan

Beth is a doctoral candidate in Early Childhood Special Education at Kent State University, completing her dissertation on the roles and perspectives of grandparents of children with special needs. Beth co-taught graduate courses and worked on a variety of research and service coordination activities. For the past year, she has served as research coordinator for the Early Childhood Research Institute on Inclusion at San Francisco State University. Beth is actively involved in TASH on many levels and is co-coordinator of the Early Childhood Interest and Action Group.

Media Awards

Film Category: John J. Michalczk, Producer of "In the Shadow of the Reich: Nazi Medicine"

This documentary studies the step-by-step process that led the medical profession in the Third Reich down the road to genocide of people with disabilities and other devalued minorities. It provides the historical basis for many current dilemmas in bio-ethical work.

Print Category: Sonny Kleinfield (not pictured), New York Times

Sonny Kleinfield eloquently put into words the story of James Velez and his family. Sonny's story captured James' journey through institutions, including BRI (Behavior Research Institute), into the community. The recent three day, front page series captured the spirit of the work of TASH members and reached millions of people around the world with both the idea and the process of community inclusion.

MORE TASH AWARD WINNERS

Positive Approaches Awards

For Community: This year's award honors James Velez (seated), Fredda Brown, Lisa Pitz, Fredda Rosen, and Sonny Kleinfield (not pictured)

They are honored for pursuing against all odds, a life in the community for James, who was institutionalized for years and received contingent electric shock in the name of treatment. James Velez, along with this family, advocated for an apartment of his own, and an effective, *positive*, system of supports. Lisa Pitz and Fredda Rosen devoted extraordinary energy toward helping James secure funds, find a place to live and work, and to identify a team to support him to achieve his dream of a life of his own. Sonny Kleinfield told James' story in a way that communicated to the world the importance of inclusion, diversity, and the importance of respectful supports.

For Inclusive Education: Nancy Caldwell-Korpela

TASH is pleased to honor Nancy, who is an extraordinary teacher at Sennett Middle School in Madison, Wisconsin. Nancy always focuses on the strengths, talents, and needs of her students. She searches out or creates positive, cutting-edge interventions, which are individually focused, and have contributed to long-lasting behavioral changes in her students. Nancy is unwavering in her commitment to inclusive education for all students, including those who have displayed the most challenging of behaviors. Nancy has made a tangible difference in many lives, and is an inspiration to the children, families, and professionals with whom she interacts.

Some of the recipients of the Collaboration Award (L-R) Judy Martz, Judith Gran, Carrie and Wayne Dyer, Sue Pratt and Jamie Ruppman.

Collaboration Award

The 1997 TASH Collaboration Award goes to a group of committed people who came together from around the country to assure that the Individuals with Disabilities Education Act (IDEA) continued to guarantee all children the right to a free and appropriate education in the least restrictive environment. This group advanced the voices of families from outside of the beltway who were being drowned out by the din of Washington politics.

Standing in the face of political realities, these folks are some of the real heroes of IDEA '97:

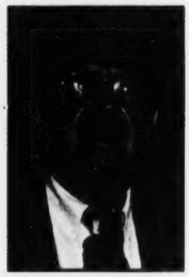
Barbara, Wayne, and Carrie Dyer, Deb Kunz, Jamie Ruppman, Tom Gilhool, Kathy Boundy, Paula Goldberg, Sue Pratt, Margaret Burley, Judy Martz, Myrna Ayres Thompson, Frank Murphy, Kathleen Marafino, Barbara Wagner, Maureen Hollowell, Judith Gran, Laurie Draves, Rene Leininger, Kerry Flynn, Lisa Baach, Bill Kienzle, Judith Raskin, Carol Blades, and Barbara O'Donnell

Special Award

Nancy Zollers is pictured with Aaron Feuerstein, who received a special award from TASH for his commitment to his workforce, the community of Lawrence, MA, and to inclusive communities.

1997 TASH Conference Keynote Address

BY REED MARTIN



Reed Martin has represented individuals with disabilities for over 25 years. With the publication of his book, Educating Handicapped Children: The Legal Mandate in 1978, he became recognized as a national voice in special education law and has testified at the request of Congress and the U.S. Commission on Civil Rights on disability issues. TASH was honored to host Mr. Martin as one of its keynote speakers during the 1997 TASH Annual Conference and offers excerpts from his keynote address.

There were some dramatic changes in the IDEA, and Congress clearly listened to this organization (TASH) and a lot of parents and advocates around the country. We were very afraid for the last 2 years of possible negative changes to the IDEA. Two years ago I thought any changes were going to take away, take away, take away. I know a lot of us thought that. But mostly the changes were positive because of the role TASH and others played in informing Congress. Much of the statute has changed in a very positive way by pulling into the statute things that had been in the regulations for many years, but parents hadn't really had effective access to because schools would say "this and that is not in the statute."

Also, Appendix C to the regulations under the IDEA had been in existence since 1981. Appendix C had been quoted by every circuit court in the United States but, again, parent after parent that I talked to who I had sent to an IEP meeting got blown off as they heard time and again, "well it's in Appendix C, use Appendix C." Well, the Congress put so much into Appendix C, the regulations, and the court cases that it really does codify a great deal of growth over the last 20 years.

So the real question is, will anybody enforce it? Will the Federal Government enforce it? Will the local districts actually enforce it? I've been in 27 states since June 4th when the Act was signed into law and what we've all seen is an awful lot of states that think the short title of this Act is the Business as Usual Act of 1997. I'm here to tell you we are not going to let anyone get away with that, particularly the Office of Special Education and Rehabilitative Services (OSERS). To go back to our theme of change, we must emphasize that enforcement must occur at the federal level. There's going to have to be a report to Congress from the OSERS and from the Department of Education — which also includes the Office of Civil Rights (OCR) – on their increased enforcement activities, as well as an annual report on what they are doing to enforce those statutes.

I feel like we need to report to Congress, as well. I'm involved in one complaint in progress right now in West Virginia where we have really got the goods on the state and a local agency, and the feds came in and danced all around it and seem to have missed the things that we had pointed out to them. On our web site we are soliciting from around the country examples of failure to monitor at the state and federal levels. Congress has said they want the federal government to report to Congress on enforcement, or lack of enforcement, and I think we need to report to Congress, too. I'm planning to do my own report at the end of this year, hopefully with the help of a lot of you, on whether OSERS and OCR have, in fact, been enforcing the law.

There will be new enforcement visibility at the state education agency level: a requirement that when a complaint is filed, the state carry out investigations, issue a written decision, provide technical assistance to the local education agency, and provide corrective actions, including compensatory education. The changes that have been made by the statute dealing with instruction are very positive. They really support teachers and anything that is going to be instructive for our kids is going to have to support classroom personnel, related service personnel, and others.

In regard to behavior, the remarks that Rud Turnbull made yesterday were very good. We must begin to deal very positively at the very earliest stage with behavior problems. The statute talks about behavior that impedes a child's learning or those of others around them. So even before we get into something that is negative like punishment for misbehavior and things like that, we are dealing early on with things that will support the teacher and enable him or her to keep the child in the classroom and reach that child. The new requirements in the individual education plan (IEP) say that we have to have "a statement of special education and related services, supplemental aids and services, program modifications or supports for school personnel." That tells me an awful lot of rich services are going to be coming into the classroom, not moving that child out of the classroom. **So we need to make sure that we win what the promise of that law is for all of our children.**

We also feel very positively about changes in the statute in regard to misbehavior. We finally have put in the statute the requirement that we make a decision whether the misbehavior is willful and, therefore, punishment in the colloquial sense would change that behavior, or is it one of two other alternatives. Is the behavior simply a manifestation of the child's disability? That is, the child is not misbehaving; they are being what they are in the classroom, and we need to address that to make it work with the other children. It's simply a manifestation. **Or has Congress now recognized in the statute that the problem of this child's functioning in the regular environment may be the inappropriateness of the program to enable that child to function appropriately in a regular environment? Either of these lead to a functional behavioral assessment, and a plan — a very positive plan — for behavioral intervention.**

Now once we get these plans, these behavioral intervention plans, they rule discipline in the local building. I don't care about school based management, and "I'm my own plan" and all of these attitudes that I run into with some of these administrators. Regular education administrators can't intervene once we have a behavior intervention plan. The

continued on page 13

CONFERENCE KEYNOTE ADDRESS

continued from page 12

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"Twenty-three years ago on the day of passage of the Education for All Handicapped Children Act, Senator Stafford said 'this thing that we do, then, is not only an act of law for equality and education, but an act of love for those extraordinary children wishing only to lead ordinary lives.' . . . make the '97 Amendments live up to that same promise."

■ ■ ■

teachers have to follow those behavior intervention plans and they are aimed at being positive. I've worked in some classrooms where they really weren't. It's amazing how much misbehavior begins to disappear when all students are treated with dignity. So we really know how to do these positive behavioral plans. What we have to do is make sure the local education agency and the state education agency provide the services to the classroom, to the teachers, to the related service and instruction personnel.

We had in the law for the last 22 years a comprehensive system of personnel development whereby any local teacher, related service person, regular education person, whoever it may be, can draw on all that we've learned and also tap into the inter-agency agreements which states must have had in place [for the last 23 years] and which assure an adequate supply of appropriately trained personnel. So we need to make sure that our local districts and our state education agencies stop cheating our teachers. **We need to give the teachers what they are entitled to, which is the knowledge from around the country of how to deal with a particular child in a particular setting in a regular kind of environment. If we give them the assistance we know we can, we can make those teachers positive behavior managers** rather than have those teachers have to rely on removal and more punitive kinds of techniques.

Now another very important change – the most radical change in the 1997 Amendments – and I had to re-read it several times and throw cold water on myself when I read it - are we're going to have accountability on the IEP. The two statements that I get from parents who call me from all over the country is we're not sure if our IEP is working or if it's being implemented. Parents may think it's a good IEP, but they're just not sure if it's working and they don't have a method of finding out. They go to school, they look for records, they try and talk to people and they are put off until the next IEP meeting. But **what Congress has now required for every child on an IEP is a written report on progress under that IEP, as often as we make written reports on non-disabled kids.**

Every 6-9 weeks we're going to be getting those kinds of written report cards. So the key for us to be able to understand it is for the IEP to contain measurable goals and measurable short-term objectives. And then, if there is not expected progress at each of those measurement periods, 6 or 9 or however many weeks, the Congress requires the IEP team to be re-convened to answer the question of why there is not expected progress toward the annual goal. Really revolutionary. We used to have to fight, yell, scream, all sorts of things to get any re-attention to any part of the IEP. Now it's going to be offered to us very easily on these report cards. We, of course, need everyone to learn to write a behaviorally descriptive IEP, or else it's going to be thrown away because a measurement of "doing as well as can be expected" is not going to help.

There are new problem solving mechanisms in the IDEA Amendments. I'll mention just two. New things in the notice. I really urge parents to go out and ask now for notice to be given to you as to changes since June 4th. It has to be given to you before an IEP meeting. It has to be given to you before certain other points, but it has to be available for the asking. I have on my web site an article called "Have You Noticed Your Notice Lately?" and it is being reprinted all over the country in parent newsletters. If you want to locate the notice, my address is in the TASH conference program book. I would love to hear from you and get you in touch with that. But the key problem-solving item in the new notice states that a group that can explain the notice and the procedural safeguard rights to the parent must be identified. Instead of having the parent get the notice and say this doesn't tell me anything, I don't understand it, the notice itself is going to have to name an organization, name an entity, name a group that will be able to explain those procedural safeguards. That group, whether it's the Parent Training and Information Center, TASH, or a local group that's started up, will hopefully use the parent's concern to work through not only the procedural safeguards, but what problems or issues concern the parent.

Another problem-solving aspect of these amendments — and there are quite a few more — is that with every hearing request now, states have to offer mediation. If the parent doesn't want to go through mediation, the requirement is that they have to be put in touch with a group (again it could be a Parent Training Center, TASH, whatever), so they can talk about the benefits of mediation. Now, I hope that once the parent who has asked for a hearing is put in touch with someone who can talk about mediation, two things might happen. First, they might get the information from folks like you who are experienced and they will be able to solve their problem short of going through the full blown hearing. Second, if they decide to go forward with mediation, they now have someone with experience who might be able to help them go to mediation and solve the problem short of going to a hearing. I'm a lawyer who's on a one-person campaign to keep parents from ever having to go to a lawyer to get their problem solved. I think we lawyers ought to support these new problem-solving mechanisms.

I will be doing a national conference this summer to come up with strategies to use these IDEA Amendments. I'll be getting a lot of information out to folks and information will be on our web site. Just for fun's sake we've named this summer's conference Nationwide Alliance of Special Education Advocates and Attorneys. We chose that name because the acronym is NA[U]SEA. So those are the kind of strategies we will be pursuing.

Now the least restrictive environment (LRE) is also dealt with in a very important way. I find whenever I talk about this

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CONFERENCE KEYNOTE ADDRESS

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a lot of people don't understand what restrictive means in LRE. It really comes out of the 14th Amendment to the Constitution and out of a U.S. Supreme Court case from 1954, not Brown v. Board of Education. The Supreme Court said when we have more than one way to accomplish a legitimate governmental objective, we have to use the least restrictive means to accomplish that legitimate governmental objective. And the term restrictive means restriction on access to what every other person in that group enjoys. It means equal protection of the law.

What the Congress has enunciated in talking about least restrictive environment is the regular curriculum and the regular environment. So we're going to be looking at does a child get to school with the same transportation that other children are given access to. When they arrive at school, do they mill around like the other children, or are they told to report to someplace that is too restrictive a means to accomplish that legitimate governmental objective? Do they change classes with other children, do they go to recess with other children, do they go to lunch with other children, do they have access to all of the courses that everyone else is offered? We have to make sure that we remove anything that is too unnecessarily restrictive. It's more than just LRE. Environment sounds like a street address. It's every element of the day that we have an opportunity to free children up and give them access to what everybody else has.

Another Supreme Court case in 1975 talked about how you can be too restrictive in school if you do something that causes psychological harm to a child or causes a feeling of worthlessness in that child. That violates the 14th Amendment's equal protection clause. We have to realize the way teachers, related service personnel, and other administrators interact with youngsters may cause too restrictive a means to accomplish a legitimate governmental objective even though the school thinks it's got the child in the right "street address" in the LRE.

For many people, the key to access to the LRE is going to be assistive technology. The 1997 Amendments hand us something that we really need to work with. The '97 Amendments say "the IEP team shall consider the communication needs of the child and consider whether the child requires assistive technology devices and services." Does anybody sense FC (facilitated communication) in there somewhere? Every child, no matter what their diagnosis, has to consider assistive technology and consider communication needs and deal with LRE. For many children, that assistive technology is going to be some kind of communication device.

Now the '97 Amendments also reemphasize inclusion as a goal and inclusion is all encompassing. Congress has dealt with inclusion really heavily with the 1990 Americans with Disabilities Act (ADA), the 1990 IDEA Amendments, the 1992 Rehabilitation Act Amendments (especially with attention to Section 504), the 1994 School to Work Opportunities Act, and in dealing with all of that they keep going back to the ADA. In 1990, Congress was about to pass an omnibus bill that would deal with every aspect of being disabled. It wasn't just looking at special education, it was about every aspect of disability discrimination in America. Congress commissioned Louis Harris, the pollster, to look at that and he did a magnificent poll, really voluminous, dealing with special education. He was looking at had special education paid off. That was 1990, that was 15 years after the Education for All Handicapped Children Act was passed in 1975. What have we done for all of these youngsters, children, and young adults with disabilities? What Harris found really caused Congress a lot of pause because the typical graduate - not everyone - but the typical graduate was not prepared for independent living. The typical graduate was not prepared for independent employment, or perhaps even employment without some degree of assistance. The typical graduate was not prepared to get access to further education or training in order to hone some particular skill, and the typical graduate was not prepared to get access to recreation and leisure in the community.

So in 1990 Congress changed the law in the IDEA by providing for transition services. What we have to realize is that those 4 global goals are now, according to Congress, what really makes sense out of anything we do in special education. If what is being done with your child in school today is not related to one of those four goals, then why are we wasting your time? If it isn't going to pay off for independent living, if it's not going to pay off for independent or supported employment, if it's not going to pay off in getting access to further education or training, and if it's not going to pay off in getting access to recreation and leisure in the community, then we're wasting that youngster's time because I assure you every goal — academic, educational, communicative, whatever – and I've done a lot of IEPs, fit under those four global goals.

Now one clear route to attaining those goals has to be self-advocacy and the ADA in 1990 really hammered self-advocacy. The 1992 Rehabilitation Act really hammered self-advocacy and the 1997 IDEA Amendments have really hammered self-advocacy. It's very clear that we want to teach persons to speak for themselves, communicate for themselves, take more control of their lives.

These are just a few of the significant changes, just a few. And a few things are not that good but we are going to be working to work around them. Many more things that are very significant I haven't even touched on. We've been worried for 20 years that Congress would come along someday and make significant changes in the Education for All Handicapped Children Act, and now it's happened and I think it's up to us to make sure that we make it work for us. **Twenty-three years ago on the day of passage of the Education for All Handicapped Children Act, Senator Stafford said "this thing that we do, then, is not only an act of law for equality and education, but an act of love for those extraordinary children wishing only to lead ordinary lives."** With this organization, I think we will be able to make the '97 Amendments live up to that same promise. Thank you.

Reed's web site is located at http://users.westco.net/~connie, or you can send an e-mail to connie@westco.net Of course, you can also contact him the old-fashioned way - (304) 296-1187!

Many thanks to all of the wonderful exhibitors who helped to make this year's conference a huge success!

AbleNet
AFB Press/American Federation for the Blind
APSE: The Association for Persons in Supported Employment
Attainment Company, Inc.
Bell Atlantic
Bible Alliance
Brookline Books, Inc.
Brookes Publishing Company
CARF...The Rehabilitation Accreditation Commission
Center for Community Inclusion, UAP
Center on Human Policy, Human Policy Press
Cole Vocational Services
Diverse City Press
Fanlight Production
Federation for Children with Special Needs
Garaventa USA, Inc.
Gary Lamb Music
Inclusion International and UNESCO Special Needs Education
Inclusion Press
Institute for Community Inclusion
Institute on Disability/UAP
Insurance Professionals of New England, Inc.
International Ret Syndrome Association
Jewish Family & Children's Service
Laureate Learning Systems, Inc.
Lesley College
LR Consulting
National Library Service BPH
National Lifetime Assistance Centers, Inc.
National Professional Resources, Inc.
New England ADA Technical Assistance Center
On-Line Connection to the 1998 International People First Conference
Peak Parent Center
Program Development Associates
REM, Inc.
Roots & Wings Educational Catalog
Sentient Systems Technology
Seven Hills Foundation
Supported Living Technologies
The Disable Hotline
The Mood Disorders Network
The Nth Degree
The Puppet Petting Zoo
Visions for Independent Living
Watersun Publishing Company, Inc.
Woodbine House
Words + Inc.

If you would like information on any of the 1997 conference exhibitors, contact Rose Holsey at 410-828-8274 ext. 100.

TASH EXHIBIT HALL

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TASH wishes to acknowledge the generous support of our newest lifetime members

★ ★ ★ ★

JACQUELINE THOUSAND
NANCY ZOLLERS

★ ★ ★ ★

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments. If you are interested in becoming a lifetime member of TASH, contact Rose Holsey at 410-828-8274, ext. 100.

The Hattie Larlham Foundation
in collaboration with Rainbow Babies and Children's Hospital
of University Hospitals Health System present

Family Vision '98

Tuesday and Wednesday, March 10 & 11, 1998,
Sheraton Suites Hotel, Cuyahoga Falls, Ohio

Join us for a comprehensive review of the forces affecting individuals with special needs. Keynote presentations include a discussion of sexuality issues related to individuals with disabilities by reknown author and lecturer **Dave Hingsburger**, and a detailed overview of managed care by **Amy Gerowitz,** president of *Outlooks*, a Cincinnati-based consulting group.

Additional sessions will address topics such as:

- *Rights/People-Centered Language*
- *The Ethics of Examination*
- *Dealing with Multiple Physicians*
- *Seizure Disorders*
- *Family Stress & Sibling Support*
- *Special Education & more ...*

If you would like to receive a conference brochure, contact Kim Skelley, Hattie Larlham Foundation, (330) 274-2272.

Innovations

Invitation for Submissions

About the Series

Innovations is a publication of the American Association on Mental Retardation that brings research to practice. Designed for busy practitioners, Innovations translates research findings into clear, usable ideas. Each issue is devoted to one topic. Recent issues have included:

Teaching Students in Inclusive Settings	by MaryAnn Demchak
Teaching Self-Management to Elementary Students	by King-Sears & Carpenter
Designing Positive Behavioral Support Plans	by Bambara & Knoster
Increasing Variety in Adult Life	by Daniel Steere

Call for Contributors

Submissions of proposals for the 1999 series are invited. Potential contributors are requested to prepare a 2-3 page proposal including a description of the topic and its importance, an outline of the content and references. If a proposal is accepted, a full manuscript will be invited for review The deadline for the next round of review is April 1, 1998. Mail 8 copies of the proposal to Diane Browder, Editor of Innovations, Lehigh University, 319A Iacocca Hall College of Education, Bethlehem, PA 18015.

JUSTIN DART

Recipient of the Presidential Medal of Freedom

Justin Dart, Jr.

On Martin Luther King's birthday (January 15), President Bill Clinton awarded the Medal of Freedom — our nation's highest civilian honor — to Justin Dart, Jr. in a White House East Room ceremony. A fitting tribute to "a real soldier of justice," it was also a landmark event: the first Medal of Freedom recognition for any member of the disability rights movement.

In presenting the Medal of Freedom to Mr. Dart, President Clinton said: "Justin Dart literally opened the doors of opportunities to millions of our citizens by securing passage of one of the nation's landmark civil rights laws, The Americans with Disabilities Act. . . . At the University of Houston, he led bold efforts to promote integration. He went on to become, in his own words, 'a full-time soldier in the trenches of justice,' touring every state in the nation to elevate disability rights to the mainstream of political discourse."

The formal citation recognizing Justin read:

"'The purpose of human society,' Dart has said 'is to empower every individual to live life to his or her God-given potential.' He has made that purpose his own. Since contracting polio as a young man, he has worked for the independence, inclusion and empowerment of people with disabilities. A leading architect of the Americans with Disabilities Act and a driving force behind its passage, he has had a profound impact on the public policy of this Nation. Justin Dart has earned our thanks for helping us recognize the possibility within each individual and for tenaciously advocating equal access to the American Dream for all our people."

TASH proudly joins President Clinton and the Nation in saluting our uniquely gifted leader, supporter and friend, Justin Dart, Jr.!

Mothers of Adults with Developmental Disabilities:

****Are you age 55 or older and sharing a home with your adult son or daughter with a developmental disability?****

DO YOU HAVE CONCERNS YOU WANT TO SHARE?

The Center on Aging at Bradley University wants to learn more about your family by conducting a confidential telephone interview with you. The interview will focus on the challenges and rewards of living with an adult son or daughter who has a developmental disability.

Knowledge gained from this study has the potential to influence services and policies for your family.

For more information call 1-800-244-4470
or write the Center on Aging,
Suite 418, Jobst Hall, Bradley University, Peoria, IL 61625

Aging
Together

DRAFT 1997 IDEA REGULATIONS

As reported in the December 1997/January 1998 edition of the TASH Newsletter, the changes in IDEA '97 require the U.S. Department of Education to write new regulations for implementing the law. The 90-day comment public comment period to respond to the draft regulations expired January 20, 1998.

TASH received many comments and opinions on the draft regulations from our members. Thank you for your valuable input. We hope together our comments can help forge a stronger set of implementation criteria. A copy of the comment letter issued by TASH to Thomas Irvin in the U.S. Department of Education's Office of Special Education and Rehabilitative Services follows.

January 20, 1998

Thomas Irvin
Office of Special Education and Rehabilitative Services
U. S. Department of Education
Room 3090
Mary E. Switzer Building
330 C Street, S. W.
Washington, D.C. 20202

Dear Tom

Enclosed please find the comments of TASH to the Notice of Proposed Rulemaking concerning the regulations governing 34 CFR Parts, 300, 301, and 303 (Assistance to States for the Education of Children with Disabilities, Preschool Grants for Children with Disabilities, and Early Intervention Program for Infants and Toddlers with Disabilities).

TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. TASH believes that no one with a disability should be forced to live, work, or learn in a segregated setting, and that all individuals deserve the right to direct their own lives. TASH's mission is to eliminate physical and social obstacles that prevent equity, diversity, and quality of life.

TASH fought valiantly to assure the rights of all children were protected in the IDEA '97. Following are specific areas of importance to TASH. These comments were developed by the Center for Law and Education and endorsed by TASH.

ISSUES:

General Curriculum—The relationship of curriculum to content should be tied to LRE (least restrictive environment). Incorporate into Section 300.12 and amend it to reflect that the definition of "general curriculum," while relating to "content" of instruction, include the maintenance of the provision of least restrictive environment, including justification for removal when appropriate.

Behavior—In reference to Section 300.22(b) Related Services. Define "functional behavior analysis" and "positive behavior support." Given the emphasis of the Amendments on effectively addressing behavior, a separate set of regulations should be developed. TASH recommends the adoption in full of the Beach Center's guidelines on behavior support: Model statute/regulation/technical assistance guidelines on Positive Behavioral Support for Students with Disabilities Who Have Impeding Behaviors.

Special Education—Special education is a set of services, not a place or a curriculum. Please add the language "supports and related services" whenever special education is mentioned and incorporate that language throughout.

CSPD (Comprehensive System of Personnel Development)—Incorporate the note that references the establishment of procedures for the acquisition and dissemination of "significant knowledge derived from educational research and for adopting, where appropriate, promising practices, materials and technology" into Section 300.135. Additional language should be added which ensures acquisition and dissemination include (but not be limited to) parents, school boards, parent training information centers, etc.

Monitoring—Enforcement, as outlined in the IDEA Amendments of 1997, needs to be more clearly delineated. There are no assurances that referrals to the Department of Justice will bring us any closer to the realization of the "promise." Regulations need to be very explicit about the expectations and consequences.

FAPE (Free and Appropriate Public Education)—The statute states that "under the Act ...there must be policies and procedures to ensure that FAPE (free appropriate public education) is available to all children with disabilities ...including children who have been suspended or expelled from school." TASH rejects the Department's definition of "children who have been suspended or expelled from school" as limited to those who have been removed "for more than 10 school days in a school year."

This is contrary to both the plain language of the statute and clear Congressional intent that there will be no denial of FAPE.

Thank you for your efforts and shared concerns. TASH appreciates the Department of Education's consideration of our views.

Sincerely,

Liz Healey
TASH Board President

GOVERNMENTAL AFFAIRS AND LEGISLATIVE ISSUES FOR 1998

The work of TASH is led by our members. We use the annual conference to seek important input on our governmental affairs (GA) activities. The GA Strand allows our members to get the latest information on relevant issues, and then provide input into our work for the coming year.

At the 1997 TASH conference, we were able to offer a GA strand which included over 20 topics related to governmental affairs and public policy. These included a number of sessions on IDEA '97, the Medicaid Community Attendant Services Act, HR 2020 (MiCASA), Assisted Suicide, Americans with Disabilities Act (ADA), Technology and Grassroots Organizing, Supplemental Security Income (SSI) issues, the Rehab Act and many others. The sessions are designed to give information that brings all attendees "to the same page" on the critical issues affecting children and adults with disabilities.

After two days of delivering information, the final day of the conference is spent seeking input from our members on TASH's direction for the coming year, and then setting the agenda accordingly. For the second year, we have convened action planning sessions with members to identify our critical issues and develop a joint proposal for strategically addressing these issues. This "needs list" and recommendations are then forwarded to the Governmental Affairs Operating Committee which, in turn, reports to the TASH Board of Directors to seek approval for the upcoming year's agenda and the commitment of resources to achieve the goals outlined.

A dedicated group of people gathered and spent a considerable amount of time identifying the needs. We were all very excited to participate in a process that ultimately led us to identify two key foci that will enable TASH to "work smart" this year AND impact our most critical issues. It was very clear to all that we need to focus on monitoring and enforcement of the Individuals with Disabilities Act of 1997 and the passage of the Medicaid Community Attendant Services Act, HR 2020 (MiCASA). HR 2020, which was introduced by Speaker of the House Newt Gingrich (R) last year, will give true choice to all Americans at risk of institutionalization in nursing homes and other facilities, as well as those already incarcerated in institutions and nursing homes.

Once the key areas were agreed to (unanimously!), the recommendations were then presented to the TASH Board of Directors and accepted. TASH will focus on IDEA implementation and passage of HR 2020 (MiCASA) during 1998, under the guidance of the GA Operating Committee's newly elected chair, Michael Auberger.

We are all very excited to see the process of receiving meaningful input from our members unfold in a very powerful course of direction. We offer our thanks to everyone who has participated and will participate in the coming year to achieve our common goals.

The recent December '97/January '98 issue of the TASH *Newsletter* focused on issues related to IDEA '97. If you have comments around either of these issues, or would like to participate in TASH's Governmental Affairs Interest & Action Group, please contact Marcie Roth, Director of Governmental Affairs and Public Policy at 410-828-8274, ext. 104 or send an e-mail to mroth@tash.org.

Special Education Service Agency
ANCHORAGE, ALASKA

The Special Education Service Agency currently has two vacancies for an Education Specialist in the following areas. For more information about our organization, contact our website at http://www.sesa.org.

Education Specialist - Autism Spectrum Disorders: Minimum Qualifications: Master's degree in education with emphasis on learners with autism spectrum disorders or Master's degree in education with emphasis on the learner with moderate/significant disabilities and extensive course work on autism; minimum of three years recent experience working with learners with autism spectrum disorders.

Experience Needed: (1) developing communication-based support strategies; (2) teaching social interaction and play skills; (3) developing programs to enhance communication skills; (4) current knowledge of assistive technology; (5) knowledge of current research and range of educational practices in the field of autism; (6) qualify for Alaska DOE Special Education Type A Certification. Excellent health; ability to travel extensively and independently in rural/remote Alaska; ability to work collaboratively and independently.

Education Specialist – Orthopedic/Other Health Conditions: Minimum Qualifications: Master's degree in education with emphasis on learners with orthopedic and other health conditions or Master's degree in education with emphasis on the learner with moderate/significant disabilities and extensive course work in orthopedic and other health conditions; minimum of three years recent experience working with learner with orthopedic and other health conditions;

Experience Needed: (1) Developing augmentative communication systems; (2) current teaching knowledge using assistive technology; (3) ability to work collaboratively and independently; (4) qualify for Alaska DOE Special Education Type A Certification. Excellent health, ability to travel extensively and independently in rural/remote Alaska.

Preferred Experience: (1) Working with preschool through high school age ranges; (2) working across student ability levels; (3) experience and/or training with students who are medically fragile; (4) experienced and/or training in traumatic brain injury; (5) training professional and/or para-professional educators; (6) inter-agency networking and collaboration.

For more information about employment or to submit a resume and letter of inquiry, please contact:

Ron Jones, Program Administrator
Special Education Service Agency
2217 E. Tudor Road, Suite 1, Anchorage, AK 99507
907-562-7372 • Fax: 907-562-0545
e-mail: rjones@sesa.org

TASH's 1997 Annual Conference was dedicated to Gunnar Dybwad. Gunnar is a long time friend and lifetime member of TASH. As a life-long advocate for the rights of people with disabilities, Gunnar has set the course for progressive and humane approaches to supporting people with disabilities around the world.

A professor emeritus of sociology at Brandeis University, Gunnar has dedicated his life to increasing international understanding of issues of inclusion and the empowerment of individuals with disabilities. Gunnar, and his late wife, Rosemary, have worked tirelessly to assure better futures for people with disabilities. It was once said of them that their output was ten times the work of any other two people.

Gunnar's delightful sense of humor, his abiding regard for people with disabilities and their families, his exhaustive knowledge of the field, and his ability to act uncompromisingly, have guided his extraordinary work with parent groups, self-advocates, organizations, and people and projects around the world.

In Gunnar and Rosemary's honor, TASH established The Gunnar and Rosemary Dybwad International Self-Advocate Scholarship Fund, which will provide monetary support for self-advocates from around the world to participate in the annual TASH conference and other opportunities for teaching, learning and advocacy.

If you would like to contribute to the Dybwad International Self-Advocate Scholarship Fund, please contact Nancy Weiss at 410-828-8274, ext. 101.

Thank You!

Our sincere thanks to the 1997 Conference Volunteers - We couldn't have done it without you!

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— DIRECTOR —
Delaware Statewide Autism Program

The Christina School District, the administering district for the Statewide Autism Program, is seeking an outstanding individual to provide leadership to the Autism Program. Doctorate in Psychology or Exceptional Children is required. Experience with students with autism and/or related significant disabilities. Position is twelve months, with an approximate salary of $80,000 to $85,000. Criminal background check and drug screening are required prior to employment with the District.

Anticipated starting date will be May 1, 1998 or other mutually agreeable date.

Items necessary for a completed application: Letter of interest, resume, transcripts, description of present assignment, and five current letters of recommendation (within last year).

Completed application items must be received at the following address by March 13, 1998: Christina School District, Personnel Services Office, 83 East Main Street, Newark, Delaware 19711.

Christina School District is an equal opportunity employer.

UNIVERSITY OF CINCINNATI

Assistant Professor-Special Education

(97UC3128) Special Education (emphasis, Moderate to Intense Certification Program), Assistant Professor, Tenure Track, beginning September 1, 1998.

QUALIFICATIONS: Requirements include an earned doctorate in special education or related field, eligibility for certification in the State of Ohio in the area of moderate and intense needs, direct involvement with children exhibiting moderate to intense needs, experience in urban public school settings with linguistically or culturally diverse students, evidence of college teaching competencies, emergent leadership skills, student mentoring skills and a well defined research agenda. Candidates will demonstrate academic background and experience in supporting school age children with moderate to intense needs in behavior, cognition and language development.

RESPONSIBILITIES: Teach graduate courses in Special Education (with an emphasis in the area of behavior management with school age children with moderate to intense needs in behavior, cognition and language development), engage in scholarly inquiry, advise students with regard to certification requirements, work in field settings, assume program leadership positions as appropriate and engage in professional, university and community service.

SALARY: Competitive and dependent upon preparation and experience.

BENEFIT PACKAGE: Includes State Teachers Retirement System, Medical Insurance Options; Dental Insurance; Time Life Insurance; Disability Insurance; Family Life Insurance; Family Life Insurance; and Tuition Remission for dependents.

LOCALE: The University of Cincinnati, the second largest comprehensive research institution in Ohio, has an enrollment of approximately 35,000 students and offers degrees through the doctorate. Located in the historic gaslight district of Clifton, the University is only ten minutes from downtown Cincinnati. With a population of nearly one million, metropolitan Cincinnati has been identified as one of the five most liveable cities in the U.S. Cincinnati offers great diversity to our faculty and students, including the symphony, art museums, the opera, dance, repertory theater, a fine zoo, major league sports teams, thousands of acres of city parks and a wide variety of cultural events. Nationally recognized public and private schools, moderately priced housing, first-class restaurants, a major international airport and a completed expressway network are among the many advantages of living in Cincinnati.

APPLICATIONS AND NOMINATIONS: To apply, send a letter of application (noting control #), vita, official transcripts and three current letters of reference to: Jerald Etienne, Special Education Search Committee, Division of Teacher Education, 505 Teachers College, Box 210002, University of Cincinnati, Cincinnati, OH 45221-0002.

Review of completed applications begins on January 12, 1998. Applications/nominations will be accepted until the position is filled.

The University of Cincinnati is an affirmative action/equal opportunity employer. Women, minorities, disabled persons, Vietnam-era and disabled veterans are encouraged to apply. UC is a smoke-free environment.

1997 TASH CONFERENCE RAFFLE PRIZE WINNERS

Each year TASH Local Conference Committee and staff gather items for a raffle at the annual conference. This is always a big hit, and was a success again last year. Many thanks to the donors and the many attendees that purchased tickets. Prizes were either given on-site, or mailed to winners. Please contact the central office if you have any questions about your prize. Congratulations to the following winners.

$25.00 Gift Certificate to Vinny Testa's Restaurant
Angie Hawkins of Chula Vista, CA

Lesley College Sweatshirt
Sue Gribbins of Louisville, KY

Boston University Sweatshirt
Bernadette Albert of Portland, ME

University of Massachusetts Sweatshirt
Claire Rosenbaum of Cumberland, RI

486 Compaq Computer (donated by Disable Hotline)
Terry Drapach of Belfast, ME

Two Nights Accommodations at the Seattle Sheraton Hotel and Towers (during the 1998 TASH Conference)
Sherry Poland of Augusta, ME

One US Airways Airline Ticket
Jane Massey of Manitoba, Canada

Pick of TASH Merchandise
Martha Underwood of Tucson, Arizona

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CENTER ON HUMAN POLICY

Selected Resources and Reports on COMMUNITY INTEGRATION

The Center on Human Policy, through its National Resource Center on Community Integration and its subcontracts with the University of Minnesota's Research and Training Center on Community Living and Responsive Systems Associates, distributes a variety of reports and resources on the integration of people with significant disabilities into community life. The project would like to make these reports available to you at cost. Due to space limitations, this is a partial listing; a complete list is available upon request.

INFORMATION PACKAGES

NEW! **Women with Disabilities: Issues, Resources, Connections, Revised** (1997) by Rannveig Traustadottir and updated by Perri Harris includes an article, "Obstacles to Equality: The Double Discrimination of Women with Disabilities," an extensive annotated bibliography, and annotated listings of resources, teaching materials, services, support groups, organizations, periodicals, and World Wide Web sites. (156 pages) $8.95

NEW! **Materials on Self-Advocacy** (1997) by Rachael Zubal, Bonnie Shoultz, Pam Walker and Michael Kennedy is an update of the 1990 information package and includes an overview article, a short listing of information available, and selected reprints. (20 pages) $2.30

NEW! **Information Package on Managed Care and Long-Term Supports for People with Developmental Disabilities** (1997) edited by Steve Taylor includes resources and materials on "managed care" for people with disabilities. The focus of this package is on long-term supports for people with developmental disabilities. The package contains a position statement on managed care, articles containing background information, and cautionary pieces about the potential dangers in managed care as well as a list of additional organizations to contact for further information. (105 pages) $5.35

Innovative Practices in Supported Living: An Overview of Organizations, Issues, and Resource Materials (1996) edited by Kathy Hulgin, with Bonnie Shoultz, Pam Walker and Steve Drake, is a comprehensive resource package on supported living. It includes examples of agencies around the country that are successfully implementing a supported living approach and a discussion of related issues, such as housing and person centered planning. It also includes an annotated bibliography of written materials and information about World Wide Web sites that address supported living issues. (66 pages) $3.95

SITE VISIT REPORTS

NEW! **Not Just a Place to Live: Building Community in Toronto** (1997) by Pam Walker and Susan O'Connor describes the creation of two housing co-ops by people with and without disabilities, as well as a support organization, NABORS. (23 pages) $2.65

NEW! **Standing With People In Support, Not Control: Training Toward Self-Reliance, Inc., Sacramento, CA** (1997) by Pam Walker describes an agency in Sacramento, CA that focuses on support of parents with developmental disabilities, support for people with developmental disabilities to manage personal assistance services, and support for people in many other areas of their lives in addition to disability. (23 pages) $2.65

Jay Nolan Community Services: The Advantages and Dilemmas of Converting Quickly from Group Homes to Supported Living Services (1996) by Kathleen Hulgin describes the strategies and challenges of changing from group homes to supported living in an agency serving people with autism and other developmental disabilities. (22 pages) $2.65

Job Path: Shifting the Focus Beyond Just Work (1996) by Kathleen Hulgin and Julia A. Searl describes how an organization in New York City began to develop alternative day services for people with severe disabilities. (22 pages) $2.70

From a Community Residence to a Home of Their Own (1995) by Pam Walker describes how the Syracuse Developmental Services Office, in Syracuse, New York, facilitated the process of home ownership for two women previously living in a community residence. (15 pages) $2.40

"Like an Angel that Came to Help Us": The Origins and Workings of New Hampshire's Family Support Network (1993) by Bonnie Shoultz is a description of New Hampshire's innovative family support services. It details the legislative history of the program as well as its implementation throughout the state, and draws lessons for others interested in developing family-centered programs. (52 pages) $3.70

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Selected Resources and Reports on Community Integration

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RESOURCE MATERIALS

NEW! **Know Your Rights! Working and the Americans with Disabilities Act (ADA)** (1997) by Mair Hall and Perri Harris is a manual designed specifically for people with disabilities who want to learn about their employment rights under the ADA. A list of relevant resources and law cases is also available upon request. (26 pages) $4.00

UPDATED!! Community Integration Policy and Practice Abstracts (1997) prepared by Julia Searl and updated by Perri Harris is the third edition of a compilation of recent journal articles relevant to community integration for people with developmental disabilities and includes topics of education, employment, policy, communication and supported living. (46 pages) $3.95

NEW! **A Chance to be Made Whole: People First Members Being Friends to Tear Down Institution Walls** (1997) complied by John O'Brien is a summary of a meeting of People First of Tennessee members and advisors and presents, in their own words, what people have learned about reaching out and being friends to people who still live in institutions, and about supporting them as they move out into the community. Their hope is that other self-advocacy groups can learn from their experiences on institution closure. (27 pages) $4.65

Serving Children with Special Needs in Your Child Care Facility (1996) edited by Julia Searl is a manual that gives information to child care providers on including children with disabilities in their facility. It includes the steps of setting up a collaborative inclusive program for preschoolers, and has numerous resources that may help the process, such as how to help staff work as a team. (46 pages) $4.95

A Checklist for Evaluating Personal Assistance Services (1993) by Connie Lyle O'Brien and John O'Brien provides a way of evaluating the effectiveness of policies and/or programs providing personal assistance services by looking at dimensions such as availability, comprehensiveness and participant control. (10 pages) $2.00

NEWSBULLETINS

Feature Issue on Supporting Diversity (Summer 1996) edited by Betty Horton, Marijo McBride and Bonnie Shoultz explores ways in which services are and could be supporting people from diverse groups. It also highlights a number of individuals who tell their own stories. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota in cooperation with the Center on Human Policy.

Feature Issue on Institution Closures (Winter 1995/96) edited by Mary F. Hayden, K. Charlie Lakin, and Steve Taylor contains national information as well as a variety of articles on closing institutions written from the perspectives of self-advocates, professionals, parents, researchers, and policy makers. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota in cooperation with the Center on Human Policy.

Feature Issue on Supported Living (Autumn 1995) is a compilation of short articles describing supported living, giving numerous examples of agency approaches to supported living, and offers the perspectives of people with disabilities about supported living. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota in cooperation with the Center on Human Policy.

Policy Bulletin on Individualized Services in New York State (1995) contains several brief articles describing examples of individualized supports in New York State. The bulletin also includes discussion of issues and challenges related to policy and practice regarding individualized supports. (22 pages)

Policy Bulletin on Safeguards (1993) addresses how safety can be increased by strengthening community and improving the assistance people receive. It also discusses the paradox of regulations. (18 pages)

Single copies of all newsbulletins are free if requested with your order. If you are interested in obtaining additional copies, please contact the Center on Human Policy.

PAPERS AND ARTICLES

NEW! **Record of The Complexities of Community Building** (1997) by John O'Brien is a record of a gathering to reflect on experiences and hopes about community building. (27 pages) $2.60

NEW! **Implementing Self-Determination Initiatives: Some Notes on Complex Change** (1997) by John O'Brien offers his reflections about complex change, generated after a review of 10 of 38 proposals submitted by states to the Robert Wood Johnson Foundation in the summer of 1996. (40 pages) $2.95

NEW! **A Tune Beyond Us, Yet Ourselves: Power Sharing Between People with Substantial Disabilities and Their Assistants** (1996) by John O'Brien and Connie Lyle O'Brien concerns creating relationships and supports that offer people the assistance they require in ways that increase their effective control of their lives. (14 pages) $2.40

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Selected Resources and Reports on Community Integration

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Disability Studies and Mental Retardation (1996) by Steve Taylor applies a disability studies perspective to the study of people labelled as having mental retardation or cognitive disabilities and examines mental retardation as a social and cultural phenomenon. The article includes an extensive annotated bibliography on mental retardation and disability studies by Steve Taylor and Perri Harris. Reprinted from Disability Studies Quarterly, 16(3), 4-13. (10 pages) $2.50

NEW! **Inclusion as a Force for School Renewal** (1995) by John O'Brien and Connie Lyle O'Brien discusses schools that include students with substantial disabilities, the authors point out how inclusion heightens awareness of schools as communities and talk about how people are learning to build inclusive school communities. (25 pages) $2.45

NEW! **The Transition to Supported Living: Realizing the Moment and Moving On** (1995) by John O'Brien is an evaluation report of Jay Nolan Community Services, an agency in California that has transitioned from group homes to supported living services. (43 pages) $3.25

Living with the Questions: Notes from a Gathering of People Concerned with Supported Living (1995) reported by John O'Brien and Connie Lyle O'Brien summarizes a discussion about supported living: the hard questions, the problematic effects of current system design, the concerns in day-to-day work, and more. (37 pages) $3.00

On Accepting Relationships Between People with Mental Retardation and Nondisabled People: Towards an Understanding of Acceptance (1989) by Steven J. Taylor and Robert Bogdan is a reprint of an article (Disability, Handicap & Society, 4(1), 21-26) that outlines the sociology of acceptance, a theoretical framework for understanding relationships between people with mental retardation and typical people. (16 pages) $3.05

EVALUATIONS AND ADVOCACY REPORTS

Evaluation of the Self-Directed Personal Services Program Operated Through Enable (1996) by Pam Walker, Steve Taylor, Julia Searl, Bonnie Shoultz, Kathy Hulgin, Perri Harris, and Mary Handley is an evaluation report of the Self-Directed Personal Services program run by Enable, in Syracuse, New York. The program, which includes people with a wide range of disabilities, includes some aspects of consumer control. At the same time, systemic constraints to control are discussed. (24 pages) $2.70

Permanency Planning in Michigan: From Philosophy to Reality (1994) by Bonnie Shoultz, Susan O'Connor, Kathy Hulgin, and Paul Newman is a study and policy analysis of Michigan's permanency planning efforts, including successes and challenges, for children with developmental disabilities and mental health needs. The report is based on interviews with parents, state and local staff members, and administrators. (67 pages) $4.35

Negotiation: A Tool for Change (1979) by Steven Taylor describes basic negotiation strategies and how they can be used to work for change. The paper outlines specific strategies for effective negotiation, including preparing for and following up on negotiation sessions. (10 pages) $2.25

Principles of Whistleblowing (1979) by Douglas Biklen and Milton Baker contains a list of suggestions for "whistleblowers," staff and others who want to call public attention to rights violations at service agencies. (5 pages) $2.10

TO ORDER THESE PUBLICATIONS, WRITE TO:

Rachael A. Zubal
Center on Human Policy
Syracuse University
School of Education
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826
FAX (315) 443-4338
email: thechp@sued.syr.edu

For postage and handling, please include 15% or $2.00 whichever is the greater amount based on the total of your order. All orders must be prepaid unless an institutional purchase order is submitted. Please make your checks payable to Syracuse University. Please note that telephone orders will not be accepted. Orders with a purchase order may be accepted by fax. PLEASE NOTE: If ordering overseas, you will be billed for any additional costs.

The preparation of this article was supported in part by the National Resource Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133D50037. No endorsement by the U.S. Department of Education should be inferred. The Center on Human Policy subcontracts with TASH for space in this newsletter.

CREATING FUTURES TOGETHER

Call for Presentations

International TASH Conference
December 2-5, 1998
(Pre-Conference Workshops & Opening Reception on December 2nd)

PUSHING THE BOUNDARIES
BREAKING
THROUGH
DISCOVERING OPPORTUNITIES
LISTENING TO ONE ANOTHER
FORMING COALITIONS
BUILDING ALLIANCES
ENVISIONING TOMMORROW
Sheraton Seattle Hotel and Towers
Washington State Convention Center
Seattle, Washington

TASH is an international advocacy association of people with disabilities, their family members, community members, other advocates, and people who work in the disability field. Our members are fighting for a society in which inclusion of all people in all aspects of society is the norm. We are an organization of members concerned with equity, diversity, social justice, human rights, and inclusion for all.

Send the Original and 3 copies of the Application and Abstract (postmarked) by March 31, 1998 to:

Denise Marshall, TASH, 29 West Susquehanna Avenue, Suite 210, Baltimore, MD 21204
Questions? Phone: 410-828-8274 ❖ *TDD 410-828-1306* ❖ Website: http://www.tash.org

Sorry, faxed or e-mailed copies cannot be accepted

1998 Priority Topics

Proposals may be submitted on any topic that relates to the inclusion of people with disabilities. The 1998 Conference Committee has identified particular interest in the sub-topic areas listed below:

- Advocacy
- Building Alliances and Coalitions
- Community Living
- NEW *Creative and Performing Arts
- Communication
- Curriculum Adaptation
- NEW Deaf Culture
- Dual Sensory Impairment
- Early Childhood
- Educational Reform
- Employment and Careers
- Family Issues
- Functional Assessment for Behavior Change
- Governmental Affairs
- Grassroots Organizing
- Higher Education
- Housing /Home of Your Own
- IDEA Monitoring and Enforcement
- IDEA '97 Regulations
- Impacting Legislation
- Inclusive Education Strategies
- NEW Independent Living Centers, Councils, or Services
- Integrated Sports
- NEW Internet and Disability
- Issues of Death and Dying
- Issues of Peace and Social Change
- Leisure and Recreation
- NEW Life Transitions & Changes in Supports for Aging Adults
- Managed Care
- Management Issues
- NEW MiCASA/Personal Assistance
- Multicultural Issues
- Paraprofessional Issues
- Personnel Preparation
- Positive Approaches to Behavior Change
- Qualitative & Quanitative Research
- Rehab Act
- Related Services in Inclusive Education
- Self-Advocacy
- Self-Determination
- Special Health Care in Inclusive Settings
- Sexuality, Romance, & Dating
- NEW Spirituality
- Transition from School to Work
- Special Health Care Needs
- Students Who Severely Challege Schools, Who Do Not Have Labels of "Severe" Disabilities
- Systems Change at the Local Level
- Systems Change at the Policy Level
- Urban Education Issues

We are planning to hold a special forum for Canadian University Faculty. If you or someone you know is interested, please contact Denise Marshall at 410-828-8274 x103 or dmarsh@tash.org

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* *Please note TASH will not be able to provide staging, lighting, etc. in session rooms.*

Guidelines for Submission

1) **TASH encourages presentations that are made through partnerships.** Panels that are composed of people with varying viewpoints; ie: self-advocates, parents, family members, researchers, graduate students, and/or professionals are strongly recommended. Panels are also encouraged to represent multicultural, under-served, and varying socioeconomic viewpoints. Presentations for consideration in the the Community Living Strand will *require* participation of self-advocates and/or family members for acceptance.

2) **An abstract must be sent along with the completed application, postmarked by March 31, 1998.** Abstracts should (1) describe the topic or issue addressed, (2) provide an overview of the content, (3) describe the importance and contributions of the session, and (4) describe the session format - i.e. skill-building, program discussion, panel, etc. Priority will be given to interactive, practical, skill-building, creative, or thought-provoking sessions.

3) **Proposal content must reflect the values and resolutions of TASH**. TASH is dedicated to disseminating information that reflects both the ideals and the pragmatic realities of pursuing the goals of equity, social justice, diversity, and full community participation for people with disabilities. The proposal title, description, and all content of presentations must use "people first" language, and must relate to supports or issues that are community-based.

4) **Please limit the abstract to 300-600 words (1 - 1 1/2 pages).** Do not send any other materials. You may submit the information on the application form or in alternate format, as long as all of the information requested is included. The form is available to download from TASH's web page: www.tash.org. You must, however, print and mail the form as per the guidelines.

5) **Please complete all sections of the form:** coordinator information, session description, and contact information for co-presenters. TASH encourages you to include a variety of co-presenters in your sessions. Please include presenters who are reasonably certain of attending. Copy the co-presenter form if necessary.

6) In requesting the session format, please keep in mind that 1 hour and 2 1/4 hour presentations are reserved for interactive workshops with an audience. **Poster sessions are table top "exhibits" that allow personalized opportunity for discussion.** These sessions are highly interactive and valuable.

7) **We strongly encourage presenters to be TASH members**. *All* presenters are required to pay conference registration fees. National TASH members, self-advocates, parents, and family members are eligible to register at a reduced rate.

8) Once received, abstracts are forwarded to three reviewers for scoring. **Proposals are rated on the following criteria:** 1) relevance to TASH mission, 2) interest to TASH members, 3) exent to which information is state-of-the-art, or cutting-edge, 4) the practicality of content, and 5) the clarity of the proposal. Scores are then tallied and ranked.

9) **A basic package of audiovisual equipment will be available in all session rooms at no charge to presenters this year.** This package includes an overhead projector and an 8x8 screen. If you require additional equipment (such as a slide projector, flipchart or markers, or TV/VCR), you may rent the equipment for the specified cost. Order forms for audiovisual equipment will be sent with acceptance letters.

10) At times letters of acceptance get lost, or go to an incorrect address. **Letters indicating if proposals have been accepted are sent in late June.** Do not assume that your proposal has not been accepted if you do not receive a letter. Call the office to check on the status of your proposal. Letters are sent to the coordinator to indicate if accepted or not accepted. It is the responsibility of the session coordinator to notify co-presenters of acceptance. Confirmation Letters are sent to *all* presenters in October.

11) **If accepted, you may not receive the session time frame or format you requested.** Session assignments are based on the recommendations of reviewers, with final approval by the conference committee. Your session may be accepted as part of an In-focus Strand or as part of a general listing of sessions. The specific session room will be scheduled closer to the date of the conference.

12) **All presenters are required to make the material for their session available in alternate format upon request.** Information on accessible formatting will be provided with letters of acceptance.

The 1998 TASH Call for Presentations is available in alternate format upon request.

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Call for Presentations ◆ 1998 TASH Conference ◆ Seattle

1998 TASH Conference Presentation Application

(please be sure the abstract is attached to this form)

Date Received: __________

Session Code: __________

SESSION COORDINATOR (1 person only): ____________________

Please list below the address which you would like in the conference program:

ORGANIZATION: ____________________

ADDRESS: ____________________ CITY: __________

STATE/PROVINCE: __________ COUNTRY: __________ ZIP/POSTAL CODE: __________

DAYTIME PHONE: __________ HOME PHONE: __________

FAX: __________ E-MAIL: __________

The above address is: ☐ HOME ☐ WORK ☐ OTHER __________

Please send my letter which indicates acceptance status to:

☐ Same as Above (*skip the next session if checked*) ☐ Use Different Address (*please list below*)

ORGANIZATION: ____________________

ADDRESS: ____________________ CITY: __________

STATE/PROVINCE: __________ COUNTRY: __________ ZIP/POSTAL CODE: __________

DAYTIME PHONE: __________ HOME PHONE: __________

FAX: __________ E-MAIL: __________

The above address is: ☐ HOME ☐ WORK ☐ OTHER __________

Session Information

SESSION TITLE (*please do not exceed 10 words*):

____

Please type a description of your presentation in 40 words or less. This description will be reprinted in the final Conference Program if accepted. TASH reserves the right to edit descriptions. Please include information on content and format of session.

Requested Session Type:

(Please check only one)

- ☐ 1 HOUR SESSION
- ☐ 2 HOUR & 15 MINUTE SESSION
- ☐ POSTER SESSION
- ☐ TASH TECH (Pre-Conference Workshops)
- ☐ SPECIAL SESSION (please explain):

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Applicable Interest Area

(This category determines which committee reviews your proposal. Please pick only one)

- ☐ ADVOCACY
- ☐ AGING
- ☐ CREATIVE/PERFORMING ARTS
- ☐ COMMUNICATION
- ☐ COMMUNITY LIVING/HOUSING
- ☐ INCLUSIVE EDUCATION
- ☐ INDEPENDENT LIVING
- ☐ EARLY CHILDHOOD
- ☐ EMPLOYMENT AND CAREERS
- ☐ ETHICS/RIGHTS
- ☐ FAMILY
- ☐ GOVERNMENTAL AFFAIRS
- ☐ HIGHER EDUCATION
- ☐ LEISURE AND RECREATION
- ☐ MANAGEMENT ISSUES
- ☐ MULTICULTURAL/INTERNATIONAL
- ☐ PARAPROFESSIONAL
- ☐ PERSONNEL PREPARATION
- ☐ POSITIVE APPROACHES
- ☐ RELATED SERVICES
- ☐ RESEARCH
- ☐ SELF-DETERMINATION
- ☐ SPECIAL HEALTH CARE NEEDS
- ☐ SPIRITUALITY
- ☐ SEXUALITY/SEXUAL EXPRESSION
- ☐ STUDENTS WHO SEVERELY CHALLENGE SCHOOLS
- ☐ TRANSITION
- ☐ URBAN ISSUES

Co-Presenter Information

NAME: ____________________
ORGANIZATION: ____________________
ADDRESS: ____________________ CITY: ____________________
STATE/PROVINCE: __________ COUNTRY: __________ ZIP/POSTAL CODE: __________
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DAYTIME PHONE: ____________________ HOME PHONE: ____________________
FAX: ____________________ E-MAIL: ____________________
The above address is: ☐ HOME ☐ WORK ☐ OTHER ____________________

Thank you for your interest in presenting at the
1998 International TASH Conference

Copy this page for additional presenters. Pass a copy of the entire application to a friend or colleague!

School of Education, Syracuse University

Education in Italy: An Inclusive Approach

May 12 – June 7, 1998

Why study inclusive education in Italy? United Nations observers cite Italy's programs as the most inclusive in the world. School site visits, art and cultural experiences, guest lecturers.

Field visits to schools in Rome, Florence, Parma, and Casanova di Carinola (a rural village near Naples).

For more program information write or call Dr. Carol Berrigan (Seminar Director), Syracuse University, Center on Human Policy, 805 S. Crouse Avenue, Syracuse, New York 13244-2280; (315) 443-4486.

The University of Washington Graduate Program trains teachers to serve the needs of pupils with significant disabilities. Emphasis on data-based, systematic instruction referenced to the requirements of natural school and community settings. M.Ed. degree plus initial teacher certification possible. Dr. Felix Billingsley, Area of Special Education, 102 Miller Hall, Box 353600, University of Washington, Seattle, WA 98195, (206) 543-1827, e-mail felixb@u.washington.edu

Doctoral Program in Special Education

Department of Special Education
University of Illinois at Urbana-Champaign

The University of Illinois at Urbana-Champaign, Department of Special Education offers challenging opportunities for preparation at the doctoral level. The program is designed individually for all students to reflect their unique interests and experiences. Participants may choose to specialize in infancy and early childhood, mild disabilities, moderate and significant disabilities, or transition, among other areas. The College of Education and Department of Special Education consistently rank among the top five to ten in the nation.

Applications for graduate studies are now being accepted for the '98-'99 academic year. For more information regarding individualized doctoral studies, financial aid, or other program opportunities, contact:

The Department of Special Education
288 Education
1310 South Sixth Street
Champaign, Illinois 61820
Phone: (217) 333-0260
http://www.ed.uiuc.edu/COE/SPED/

The Facilitated Communication Institute at Syracuse University

announces the

the Sixth Conference on Facilitated Communication
"No Time For Silence"

May 4-5, 1998 • Preconference Day: May 3 • Syracuse, New York

The theme of the conference arises from the position of Facilitated Communication, which is at the crossroad between silence and voice, between inaction and possibility. The conference will focus on the latest research, practice and current issues in Facilitated Communication.

FEATURED SPEAKERS INCLUDE:

Donna Williams

Donna Williams, author of "Nobody Nowhere" and "Somebody Somewhere" will present on (Monday, May 4). Exposure Anxiety: The Problem Of Daring To Be.

Eugene Marcus

Eugene Marcus, Associate, Facilitated Communication Institute will present "On Almost Becoming a Person" (Tuesday, May 5)

Lou Brown

Lou Brown, Professor, University of Wisconsin at Madison will present on "Integrating Students with Significant Disabilities in Schools and Communities" (Tuesday, May 5)

Rosemary Crossley

Rosemary Crossley, Director, DEAL (Dignity, Education, Advocacy and Language) Communication Center in Australia, and author of "Facilitated Communication Training" and "Speechless" will speak on "Breaking the Silence" – an examination of the reactions of professional establishments to the introduction of new communication techniques, including sign language, augmentative communication and facilitated communication. (Monday, May 4)

REGISTRATION INFORMATION: You can register by phone (315) 443-4696, or complete the registration form below and return it to: Facilitated Communication Institute, 370 Huntington Hall, Syracuse, NY 13244. Completed registration forms can also be faxed to (315) 443-5845

ACCOMMODATIONS: For hotel accommodations, contact the Sheraton Inn University directly at (315) 375-3000.

FEES: Please check all boxes that apply. If you are registering for one day only, please write the day you will attend.

ADDITIONAL CONFERENCE INFORMATION available on our web page: http://soeweb.syr.edu/thefci

Conference registration includes Monday night dinner

Full Registration	$175.00
One Day Registration	$100.00 ______________
Sunday Pre-Conference	$ 35.00

Total Enclosed $__________________

(Payment must be enclosed with registration)

— SCHOLARSHIPS AVAILABLE —
Please send written request (including statement of need) to Marilyn Chadwick via surface mail or to mack@sued.syr.edu.

Name of Registrant______________________

Agency/Company______________________

Mailing Address______________________

City______________________

State/Zip or Postal Code______________________

Country (if outside of the U.S.)______________________

Phone ______________ Fax ______________

E-mail______________________

Please specify needs for interpreter services, accessiblity supports or dietary requirements______________________

Rich Villa and Norman Kunc present

THE INCLUSION PUZZLE: Fitting the Pieces Together

A two-day workshop on The Philosophy, Instructional Strategies, and Organizational Practices of Inclusive Education

When: March 24 & 25, 1998
(in conjunction with the annual CAL-TASH Conference)
Where: Doubletree Hotel, Sacramento, California

For more information, contact
MARK DOYLE
at Everyone Is Welcome: 630-584-0970

Beit Issie Shapiro's 2nd International Conference on Development Disabilities in the Community

Interdisciplinary Perspectives: Policy, Practice and Research

June 29-July 2, 1998
Holiday Inn Crowne Plaza Hotel, Jerusalem, Israel

For further information, please contact:
Conference Secretariat
CARMEL Organizers of Conferences & Events
P.O. Box 1912, Ramat Gan 52532, Israel
Telephone: +972-3-5754040; Fax: +972-3-5753107
e-mail: tcarmel@netvision.net.il

1998 Inclusion Works! Conference Accepting the Challenge... Building Partnerships

March 1-3, 1998
Renaissance Austin Hotel
Austin, Texas

More than 100 workshops will include topics of interest to parents, educators, paraeducators, and administrators. Call or e-mail us for a complete list of workshops and registration information.

Fees: $130 (professionals);
$15 (parents);
principals on a team of five or more get in FREE!

For further information:
Call 800-252-9729;
E-mail:
training@thearcoftexas.org;
Visit our web site:
www.thearcoftexas.org

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

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Address ______

City/State/Zip ______

Telephone (   ) ______ Fax (   ) ______

E-mail ______

Please Check Appropriate Categories
(not more than three)

( ) Administrator/Adult Services
( ) Administrator/Eduction
( ) Administrator/Other
( ) Adult Service Provider/Staff
( ) Behavior Specialist
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( ) Early Childhood Services
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( ) Parent/Family Member
( ) Personal Assistant
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( ) Psychologist
( ) Regular Education Teacher/
Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support
Specialist
( ) Staff Development/Trainer
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( ) Other

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Lifetime Member	$1000

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Card Number ______

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What, in particular, inspired you to join ______

What other disability organization do you belong to ______

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Student I.D. Number ______

Anticipated year of completion ______

( ) Add $15 if you would like to become a member of your local TASH Chapter

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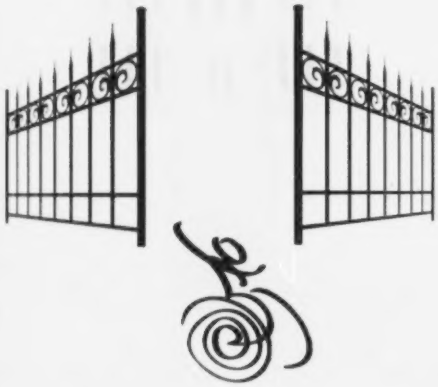
TASH
Newsletter

VOLUME 24 ISSUE NUMBER 3 MARCH 1998



From Institutional Closures...

...to a HOME of My Own

INSIDE:
MICASA,
Institutional Closure
Studies, and the
Coffelt Lawsuit

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105 or e-mail: info@tash.org

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

–

Building communities in which no one is segregated and everyone belongs;

–

Forging new alliances that embrace diversity;

–

Advocating for opportunities and rights;

–

Eradicating injustices and inequities;

–

Supporting research and disseminating knowledge and information;

–

Promoting inclusive education;

–

Supporting progressive legislation and litigation; and

–

Promoting excellence in services

TASH Considers a Name Change

FROM THE EXECUTIVE DIRECTOR
BY NANCY WEISS

For a number of years there has been discussion about changing TASH's name. Staff and Board members regularly receive negative comments about TASH's name. A common theme of these comments is: "Why does one of the most progressive disability organizations in the world have one of the most regressive names?" It seems that no one likes the name, but we have been reluctant to give up the acronym because it is so widely recognized, because to change it might lead to confusion and loss of members, and because a name change could mean considerable expense in reprinting all of our letterhead, various envelope styles, labels, business cards, etc.

In 1995, the Board voted to drop the full name (The Association for Persons with Severe Handicaps) and go by the acronym alone. None of our letterhead, business cards etc. now carries the full name of the organization. They read "TASH" and a tag-line. The tag-line currently being used is: "Disability Advocacy Worldwide."

The fact is, using the acronym alone, just doesn't work. TASH continues to be

continued on page 3

WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on the conference, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions or advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

FROM THE EXECUTIVE DIRECTOR

continued from page 2

called The Journal of the Association for Persons with Severe Handicaps. Several times a week, I explain the history of name changes in answer to the question, "What does TASH stand for?" We have received so many annoyed phone calls saying, "I've searched all over this brochure and can't find what TASH stands for," that we've started putting the following information on brochures:

What Does TASH Stand For??

Many people want to know what the acronym TASH stands for. Here's a brief history of the organization's names. When TASH was started in 1974, it was called the American Association for the Education of the Severely/Profoundly Handicapped and went by the acronym: AAESPH. In 1980 the name was changed to The Association for the Severely Handicapped, reflecting TASH's broader mission. The name was changed to The Association for Persons with Severe Handicaps in 1983 but the acronym, TASH, continued to be used. In 1995, the Board voted to maintain the acronym because it was so widely recognized but to stop using the full name of the organization as it didn't reflect current values and directions. What does TASH stand for? Probably the best answer is: equity, diversity, social justice and inclusion!

So even though we have officially dropped the offensive terms inherent in the name, "The Association for Persons with Severe Handicaps," they live on -- and clearly, are not in keeping with the values of our organization.

The Executive Committee of the Board recently approved a proposal to officially change TASH's name. The full Board is now in the process of voting on the proposal. If approved by the Board, the name change proposal would then be brought to the membership for a vote of the members. The proposal for a name change is as follows:

1. That we officially change the name of the organization to:

   "The Association for Social Justice and Human Rights"

2. That we continue to use the acronym, "TASH" and the by-line, "Disability Advocacy Worldwide" on our printed materials. We can add "The Association for Social Justice and Human Rights" to printed materials as we have them reprinted but we could continue to use paper goods we have on hand.
3. That we continue to publish the explanation above, "What does TASH Stand For," including information on the newest name change so people can understand the various changes the organization and its name have gone through.
4. That JASH officially change its name to "The Journal of The Association for Social Justice and Human Rights."

Although this name change won't solve all of our name-related problems, at least it will put the worst of the implications of our current name behind us. Some people have pointed out that the new name doesn't exactly spell TASH, but nor does The Association for Persons with Severe Handicaps! Another shortcoming is that the name doesn't clarify our commitment to disability issues. We would continue to need a tag line to make it clear that we are first and foremost, a disability advocacy organization.

I welcome your comments! You can contact me by phone (410-828-8274, ext. 101), or e-mail (nweiss@tash.org), or mail or fax (410-828-6706) a copy of this page with your responses to the questions to the right. THANKS!

1. Do you think we should pursue a name change?

2. Do you like the suggested name or have other suggestions?

3. Do you like the current tag line, "Disability Advocacy Worldwide" or would you suggest a different one?

4. Additional comments/concerns:

Name and contact information
(Optional)

SUPPORT MiCASA NOW!

MiCASA Marches Forward

On June 24, 1997, HR 2020, the Medicaid Community Attendant Services Act (MiCASA) was introduced by House Speaker Newt Gingrich. If enacted, this bill would give people the option to choose to live in the community and have Medicaid dollars provide for their support needs in the living arrangement of their choice.

TASH has joined with a host of other national advocacy organizations to endorse passage of this bill. At TASH's Annual Conference in December, passage of MiCASA was identified as a top priority for TASH's work in 1998.

There is a similar bill in the Senate, Longterm Care Reform and Deficit Reduction Act, S 879, introduced by Senator Feingold. Despite some confusion about the companionability of the two bills, TASH supports both bills, but has chosen to put its focus on the more sweeping legislation contained in HR 2020 — MiCASA.

The House Commerce Committee is currently analyzing HR 2020, and will hold hearings on Capitol Hill on March 12, 1998.

Mike Auberger, National ADAPT Leader, TASH Board Treasurer and Chair of the TASH Governmental Affairs Operating Committee, offers the following analysis of the importance of passage of MiCASA:

"This national legislation would require all 50 states to provide personal assistance services in the community for eligible individuals when those individuals prefer to live in the community. Those eligible individuals will fall into two categories. The first is individuals living in nursing homes, intermediate care facilities or mental health facilities. These folks would be able to leave those institutional settings and move into the community — funded by the dollars that were spent on them in the institution — essentially redirecting institution dollars into the community. The second category would be individuals who would be in jeopardy of institutionalization in a nursing home, intermediate care facility, or mental health facility. This would mean that eligible individuals would be able to stay in the community and not be forced into institutions.

What does this mean for parents? It means if your child or adult child was in jeopardy of institutionalization, there would be a solution in the community. If your child was in a facility and wished to live in the community, he or she could.

Passage of MiCASA also means that if you are an individual with a disability, you have a choice. MiCASA would create a choice where one currently does not exist. MiCASA would not replace any programs, and would not force anyone to choose a community alternative, but it would mean that — finally — anyone who wants to live in the community can make that choice."

■ ■ ■ ■ ■

> **MiCASA would simply create a choice, where one currently does not exist. MiCASA would not replace any programs, and would not force anyone to choose a community alternative, but it would mean that — finally — anyone who wants to live in the community can make that choice.**

■ ■ ■ ■ ■

MiCASA IS BASED ON TWELVE PRINCIPLES

1. Maximum control of the individual to select, manage, and control his/her attendant services.
2. Community-based, not institutional-based support
3. Eligibility is based on functional need, regardless of age and/or disability.
4. Services will be available in-home and other locations.
5. Services will be available 24 hours a day, 7 days a week.
6. Back-up and emergency services must be available.
7. The program must allow for co-pay or cost sharing for people with higher incomes.
8. Delivery of service must include options for vouchers, direct cash payment, individual provider model, as well as individual-directed agency model.
9. Health-related tasks can be assigned, delegated to, or be done by unlicensed personal attendants.
10. Volunteer training should be available for people with disabilities or eligible individuals.
11. Personal attendants must receive a livable wage and benefits.
12. Attendant services should be based on an agreed upon individualized service plan.

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MiCASA Marches Forward

continued from page 4

We've attempted to provide answers to some of the most frequently asked questions about eligibility and coverage criteria under MiCASA and how the program operates.

1. How are "attendant services" defined in MiCASA?

In HR 2020, also known as MiCASA, "qualified community-based attendant services" are to be defined by the Secretary of Health and Human Services. In the June 1, 1995 draft CASA bill, attendant services was defined as:

"any action to assist a person with a mental and/or physical disability in accomplishing activities of daily living (ADL), instrumental activities of daily living (IADL) and health-related tasks. These include, but are not limited to: personal care services, household services, cognitive services, mobility services and health-related tasks."

Attendant services as defined in MiCASA are part of a larger system of personal assistance services. MiCASA specifically states that services should be delivered, "*in the most integrated setting appropriate to the needs of the individual.*"

2. Do you have to be impoverished to be eligible for MiCASA?

No. If you are eligible to go into a nursing home or an ICF-MR facility, you would be eligible for MiCASA. Financial eligibility for MiCASA can go up to the current Medicaid eligibility for nursing homes, which is 300% of the Federal poverty level. In addition, states can choose to implement a sliding fee scale for people of higher incomes, and MiCASA specifically references this as an incentive for employment. This sliding fee scale can go beyond the current Medicaid eligibility guidelines.

3. Is MiCASA biased towards an agency delivery model?

No. MiCASA assumes that "one size does not fit all." It allows the maximum amount of control preferred by the individual with the disability. It allows for vouchers, direct cash payments or use of a fiscal agent in obtaining services, in addition to services delivered by an agency.

In all these delivery models the individual has the ability to select, manage and control his/her attendant services. The key concepts are choice and control regardless of who the employer of record is.

4. Will MiCASA replace existing community-based programs?

MiCASA creates a new service that people who are eligible for nursing homes and intermediate care facilities can choose. The money follows the individual rather than staying with the facility. MiCASA does not effect existing programs or waivers. Waivers usually include a much more intense package of services for those individuals who need that package. MiCASA establishes attendant services as a unique service that can compliment other services.

5. What are the transitional services?

Currently Medicaid does not pay for some needed services for people coming out of nursing homes and intermediate care facilities. These include rent and utility deposits, bedding, kitchen supplies and other things necessary to make the transition into the community. These costs would be covered by MiCASA.

6. What is the purpose of the transition plan?

MiCASA also sets aside $2 billion over 6 years to help the states transition from their current service model to more community-based services. The bill brings together the major stakeholders in the fight for community-based attendant services. The DD Councils, Independent Living Councils, and Councils on Aging would develop a plan that would transition the current system into one that focuses on community-based attendant services. Closing institutions, or at least the closing of bed spaces, must be thought through by the people that have an investment in the final outcome – the consumers. The plan envisions ending the fragmentation that currently exists in our long-term care system.

Please send an individual letter to each House member listed below and ask him/her to support passage of HR 2020-MiCASA.

To send letters, you can obtain e-mail, fax and post office addresses for individual Committee members at the Commerce Committee web page: http://www.house.gov/commerce/welcome.html or you can call the Committee at: (202) 225-2927.

How can you help support passage of MiCASA?

Following is a list of the members of the House Commerce Committee, the Congressional body currently analyzing HR 2020 (MiCASA):

Republicans:

Tom Bliley, VA, Chairman
W.J. "Billy" Tauzin, LA
Michael G. Oxley, OH
Michael Bilirakis, FL
Dan Schaefer, CO
Joe Barton, TX
J. Dennis Hastert, IL
Fred Upton, MI
Cliff Stearns, FL
Bill Paxton, NY
Paul E. Gillmor, OH
Scott L. Klug, WI
James C. Greenwood, PA
Michael D. Crapo, ID
Christopher Cox, CA
Nathan Deal, GA
Steve Largent, OK
Richard Burr, NC
Brian P. Bilbray, CA
Ed Whitfield, KY
Greg Ganske, IA
Charlie Norwood, GA
Rick White, WA
Tom Coburn, OK
Rick Lazio, NY
Barbara Cubin, WY
James Rogan, CA
John Shimkus, IL

Democrats:

John D. Dingell, MI
Henry A. Waxman, CA
Edward J. Markey, MA
Ralph M. Hall, TX
Rick Boucher, VA
Thomas J. Manton, NY
Edolphus Towns, NY
Frank Pallone, Jr., NJ
Sherrod Brown, OH
Bart Gordon, TN
Elizabeth Furse, OR
Peter Deutsch, FL
Bobby L. Rush, IL
Anna G. Eshoo, CA
Ron Klink, PA
Bart Stupak, MI
Eliot L. Engel, NY
Thomas C. Sawyer, OH
Albert R. Wynn, MD
Gene Green, TX
Karen McCarthy, MO
Ted Strickland, OH
Diana DeGette, CO

The Committee's e-mail address is commerce@mail.house.gov or you can send a fax to 202-225-1919

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No single issue in school reform has created more controversy or continuing debate than the inclusion of children and youth with disabilities in regular education. To assist professionals and parents in obtaining critical information, National Professional Resources, Inc. provides you with the latest information! Published 5 times per year, *Inclusion Times* provides the latest information on:

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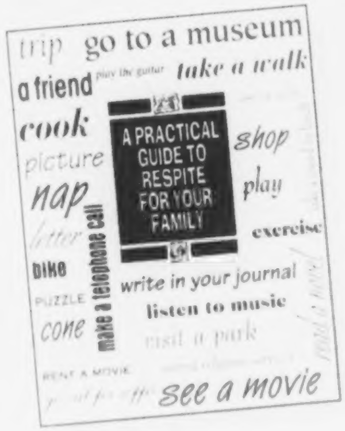
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TASH Member Directory

We are currently working on publishing a TASH Member Directory, targeted for release in January 1999. The directory will list members by last name, by state and chapter affiliation, and by Interest and Action Group.

In addition, because we often get requests to refer speakers and consultants on specified topic areas, we will also include a section listing TASH members available for consulting and speaking. If you would like to be listed in this guide in a consultant/trainer capacity, please send the following information:

Name ____________________
Address (list the preferred directory address) ____________________
This is my Home Business Other ____________________
Phone Number __________ Fax Number __________ E-mail address __________
Web page ____________________

Please list up to three topic areas that you would like to be referenced under:
1 ____________________
2 ____________________
3 ____________________

Please list in what capacity you are available (ie: consultant, speaker, reviewer)

Send to Denise Marshall, TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or e-mail the information to dmarsh@tash.org

Remember - only current TASH members will be listed in this valuable resource. If you know of speakers or consultants who are excellent resources, encourage them to become members now!

Institution Closures Continue at an Average of More than 12 per Year

BY K. CHARLIE LAKIN, LYNDA ANDERSON, ROBERT PROUTY AND JENNIFER SANDLIN
UNIVERSITY OF MINNESOTA

It has been 19 years since the Center on Human Policy at Syracuse University issued "The Community Imperative: A Refutation of All Arguments in Support of Institutionalizing Anybody Because of Mental Retardation." The Imperative was revolutionary in its demands and threatening in its implications. How could people believe it reasonable that all 141,500 people in state institutions, over three quarters of whom were reported to have severe or profound mental retardation should live in the community? Today, the Community Imperative reflects a mainstream, although far from universal, professional point of view. It has become a passionate cause of self-advocates. It is official policy of a growing number of states. At the time the Community Imperative was drafted there were over 140,000 residents in state developmental disabilities institutions. Today, state institutions house less than 40% of the total number of residents there were in 1979. All across the U.S., in steadily growing numbers, state institutions have been closed. Each of the closures represents another step toward the fundamental proposition of the Community Imperative that, "All people, regardless of the severity of their disability, are entitled to community living." This brief report counts steps taken and left to be taken toward fulfillment of the Community Imperative.

The statistics were provided from each of the states on large state developmental disabilities institutions and special units in psychiatric facilities that have operated since 1960 and their present and projected operational status. As by convention, the definition of "institution" used is that 16 or more people live in it.

Total Large State MR/DD Institution Closures

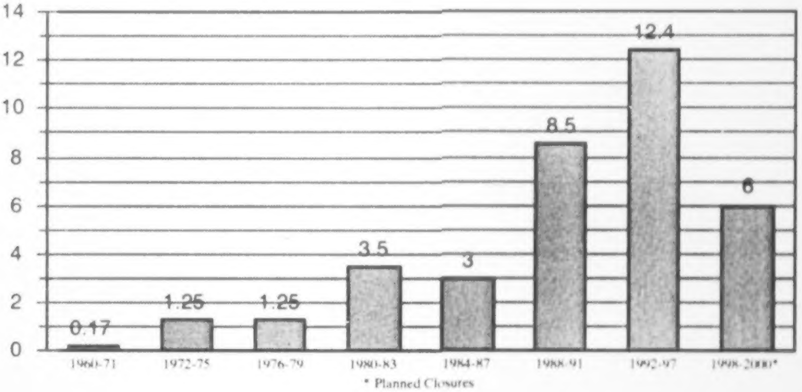
Figure 1 shows the number of large state institutions and special developmental disabilities units in state institutions primarily serving other populations that have closed since 1960. It also includes projected closures for the period 1998 to 2000 that were formally planned at the end of 1997. As shown between 1960 and 1971 only two state institutions were closed in the United States, an average of 0.17 closure per year. In Fiscal Years 1972-1975, institutional closures inched slightly upward, averaging 1.25 per year. There were 5 large state institution closures in the period Fiscal Years 1976-1979 (an annual average of 1.25 per year). There were 14 large state institution closures in the period Fiscal Years 1980-1983 (annual average of 3.5 per year) and 11 in the period Fiscal Years 1984-1987 (annual average of 3.0). In the period Fiscal Years 1988-1991, closures increased rapidly to 34 (an average of 8.5 per year). In the Fiscal Years 1992-1997, closures averaged 12.4 per year to a total of 62.

At the end of 1997 states had planned the closure of a total of an additional 18 state institutions and developmental disabilities units for Fiscal Years 1998-2000 (or an average of 6 per year). As in the past, the number of closures that will actually occur between

continued on page 9

FIGURE 1

Average Annual Number of Large State Institutions and MR/DD Units Closed and Planned for Closure: 1960-2000



Institution Closures Continue at an Average of More than 12 per Year

continued from page 8

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Three quarters of the states (38) have either closed a large state MR/DD facility or are planning to do so by the end of 2000.

—

1998 and 2000 is likely to significantly surpass the number projected at the beginning of that 3 year period.

Six states (Alaska, District of Columbia, New Hampshire, New Mexico, Rhode Island, and Vermont) no longer have large state-operated institutions. Two states (Hawaii and West Virginia) plan to close the last of their state institutions by the end of 1998. Other states continue to close institutions and move closer to ending state institution services. Maine operates a single state institution with only 17 current residents (barely an "institution" by the conventional standard of 16 or more residents). Michigan has closed 11 of its original 13 large state facilities. Minnesota is projected to have closed all but one unit of its original 9 state institutions by the end of the century. New York which had already closed nearly half of its large state facilities by 1995, has planned to close two more of its remaining 11 traditional state institutions by the year 2000. Pennsylvania having already closed 13 of 23 large state residential facilities, plans to close at least 3 more by 2000.

Closures and Projected Closures by States

Table 1 presents a state-by-state breakdown of the total number of large state facilities and units operated since 1960, the number closed between 1960 and 1997, and the number planned for closure by the year 2000. As shown, three quarters of the states (38) have either closed a large state MR/DD facility or are planning to do so by the end of 2000. In the 38 year period from the beginning of 1960 through the end of 1997, 36 states closed one or more facilities. It is projected that by the end of the century, 45% of all state institutions that have operated since 1960 will have been closed.

Source: Sandlin, J., Prouty, R., Lakin K.C., & Anderson, L. (1998). Large state MR/DD residential facility closures, 1960-2000. In R. Prouty & K.C. Lakin (Eds.). *Residential services for persons with developmental disabilities: Status and trends through 1997.* Minneapolis: University of Minnesota, Research and Training Center of Community Living/Institute on Community Integration (UAP).

TABLE 1

Summary of Large State-Operated MR/DD Residential Institutions and Units since 1960, including Closures and Planned Closures

State	Large State-Operated MR/DD Institutions and Units Operating between 1960 and 1997	Total Closed 1960-1997	Planned Closures 1998-2000
AL	5	1	0
AK	1	0	1**
AZ	4	3	0
AR	6	0	0
CA	11	5	0
CO	3	1	0
CT	15	7	0
DE	1	0	0
DC	3	3	0
FL	10	2	0
GA	8	2	0
HI	2	1	1
ID	1	0	0
IL	17	6	1
IN	11	3	2
IA	2	0	0
KS	4	1	1
KY	5	2	0
LA	9	0	0
ME	3	2	0
MD	9	5	0
MA	11	4	1
MI	13	11	0
MN	9	5	3
MS	5	0	0
MO	16	10	0
MT	2	0	0
NE	1	0	0
NV	2	0	0
NH	2	2	0
NJ	11	3	1
NM	3	3	0
NY	27*	13	2
NC	6	1	0
ND	2	1	0
OH	23	11	0
OK	4	1	0
OR	3	1	0
PA	23	13	3
RI	3	3	0
SC	5	0	0
SD	2	1	0
TN	5	0	1
TX	15	2	0
UT	1	0	0
VT	1	1	0
VA	8	3	0
WA	6	1	0
WV	4	3	1
WI	3	0	0
WY	1	0	0
U.S. Total	347	137	18

* includes only the Developmental Centers operated by New York State Office of Mental Retardation and Developmental Disabilities

** Closed last institution in early 1998

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California foes of community living fight de-institutionalization

FIGHTING TO KEEP 'EM IN

BY JOSIE BYZEK

The headlines are startling:

Selah, Washington: "Unattended Woman Dies of Brain Injury"
Chicago, Illinois: "Retarded Woman Alone In Apartment Dies of Seizures"
Omaha, Nebraska: "Retarded Man Dies After Moving to Community Care"

Fourteen pages of news clips documenting accidents and mishaps at group homes around the nation.

These form the centerpiece of a report put out by the California Association of State Hospital Parent Councils for the Retarded (CASH/PCR). This report, and a study by University of California statistician David Strauss, are the big cannons in the war to stop the exodus of Californians labeled with severe mental retardation from institutions to the community.

Besides CASH/PCR, and the usual unions representing institution workers such as the California Association of Psychiatric Technicians, the institutions have the backing of the California Medical Association, the California Arc, the *San Francisco Chronicle* - which ran an anti-community series of articles last winter - and Senator Diane Feinstein, usually noted as a liberal supporter of civil rights.

They want a two-year moratorium on all moves out of the institutions, called Developmental Centers. Feinstein "was against the transfer of people with developmental disabilities out of care. They were being kicked out into the streets. She expressed her outrage," said a staffer for Senator Feinstein in her Washington, DC office. Even though no one has been able to cite a single example of someone actually being "kicked out" of California Developmental Centers "onto the streets," Sen. Feinstein's reaction is typical.

California has had the fastest deinstitutionalization of any state so far - 2,300 people since 1994. This exodus was the result of what is called the "Coffelt Lawsuit," brought by parents of people living in the Developmental Centers, who charged that over 2,000 people in these centers wanted community services instead. When the parents won the suit, the exodus began.

The Strauss report was published in July 1996. Dr. David Strauss, a statistician for the University of California, Riverside, found that people with developmental disabilities had a 72 percent higher chance of dying in the community than in an institution. The report was funded primarily by the federal government; some money came from what Strauss calls "allied groups" - the California Association of Psychiatric Technicians is named as the primary union underwriter.

Fear of people with mental retardation living on the streets, coupled with the Strauss report, has stirred up worries of a repeat botched deinstitutionalization process like the one California experienced under Gov. Ronald Reagan when thousands of psychiatric survivors were freed from institutions without adequate funding or community supports and many became homeless.

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Repercussions from what's currently happening in California have been felt across the nation from Tennessee to Pennsylvania. The Strauss report is being touted by such pro-institution groups as Voice of the Retarded (VOR), a parent organization, as definitive proof that people with mental retardation are much better locked up than loose in the community.

Had there been no Strauss report, most likely there'd be no move for a California moratorium on people with disabilities moving out of institutions into the community. Senator Feinstein would not so firmly believe that lives are at stake, or that people with mental retardation are being forced out onto the streets. The *San Francisco Chronicle's* series on community versus institution wouldn't have had the same bite - it probably wouldn't have even been written.

But the report, coupled with the anecdotal evidence of community placement gone wrong, has brought the exodus from California institutions to a virtual halt, even without a formal moratorium on moves into the community.

"There is no credible evidence of a mortality crisis among those who are placed in community care settings," writes Dr. Jane Mercer in her report, "Statistics Should Not Undermine Freedoms for Developmentally Disabled Californians." Mercer, a sociologist, is also from the University of California at Riverside.

Her report, compiled in the wake of the Strauss report, was released last July, a year after the Strauss report. "The statistics on death rates are incomplete and certainly misunderstood," it says. Mercer's report received no press at all, in stark contrast to the Strauss report.

Mercer's report outlines the history of California's most recent move from institutions: that in the 1980s, a group of parents grew tired of waiting for the state to create placements for their children with developmental disabilities in the community and sued the state of California. This resulted in the 1993 Coffelt settlement, in which the California Department of Developmental Services agreed to move at least 2,000 people with developmental disabilities from state developmental centers into the community in five years. California lived up to its agreement – which sparked the backlash documented and supported by the *Chronicle*.

"There is no credible evidence of a mortality crisis among those who are placed in community care settings," writes Dr. Jane Mercer in her report, Statistics Should Not Undermine Freedoms for Developmentally Disabled Californians."

Mercer's report insists there's "encouraging evidence that the community placement has enriched the lives of many developmentally disabled persons." As part of the Coffelt agreement, Dr. James W. Conroy, Ph.D., an independent evaluator, has been conducting a study of the effects of community placement on those moved into the community. (See pages 18-22 of this TASH *Newsletter*.) The Conroy study did not receive any mention in the *Chronicle* series, either.

Conroy matched 118 "movers" with 118 "stayers" of the same age and sex and with similar levels of disability and found, not surprisingly, that the movers indeed were now able to get out more and socialize; that they had friends, went to church, attended school, went to the mall and other places people socialize.

"The great victory is that 2,300 people have gotten a shot at life outside an institution," says Conroy. "Those who can speak to us are very happy about it. Those who can't speak - we've measured every quality of their lives: behavioral progress, physical aspects of homes, integration, employment, and so on. I've talked to thousands of people. Everybody says they're doing great, they'd never go back. So what is this commotion about? It's bizarre!"

Conroy thinks the Strauss report will be debunked. "The essence of science is replication," he says. "No one has replicated his findings, certainly not I."

The Strauss report, he said, found a 72 percent higher mortality rate in folks who moved out of institutions - whether they lived in group homes or with mom and dad made no difference. This finding seems very odd to people like Conroy. In his own research, Conroy said, "I get the total opposite." That's why, he said "you can't just depend on one researcher. Other researchers have to find it out in other states."

"The great victory is that 2,300 people have gotten a shot at life outside an institution," says Conroy.

He compares the Coffelt settlement with the 1978 Pennhurst case in Pennsylvania, which moved over 1100 people into the community, and which he evaluated. "I tracked all those [Pennhurst] people every year right up to today. There's no question of 'in the community' or 'institution,' because everyone went to the community. Based on past years, 15 per thousand people per year die in institutions. By 1990, 182 people would have died. Instead, all those people moved into the community and only 132 people actually died."

Originally the project Strauss worked on was run by Dr. Richard Eyeman. He retired and the project was continued by

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Strauss, who was advised to do a mortality investigation. "He did so," says Conroy, "but with very complicated mathematical models. After his adjustments, he claimed that the rate of death is higher in the community than in institutions."

Another researcher with the same data would get very different results, Conroy thinks. "Cold fusion was published," he points out, "and found to not be true. It was a great stir, a huge controversy, widely published, but never replicated."

Yet, the Strauss report remains a powerful gun. The finger on the trigger of that gun is the Voice of the Retarded, a small but potent pro-institution group that has strong ties with unions representing institution workers. California CASH/PCR is allied with VOR.

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"The attempt at reconciliation and finding common ground has failed because of bad faith with VOR and CASH/PCR," says Conroy. "They come to the table, negotiate compromises, then betray them behind your back. They've done this in Pennsylvania, Montana, Tennessee, Florida and Connecticut. They have us running scared right now, but the facts are so far in our favor, so clear. Thirty years of research, there has never been a contradictory finding."

Conroy spoke with Ed Bradley from *60 Minutes* a few years ago, during filming of a story on state institutions. He says Bradley told him that as of 1995, VOR had a $1.3 million war chest. Yet, the group appears to have only 600 members nationwide. Some VOR leaders, such as Polly Spare in Pennsylvania, are open about receiving funds from unions that support workers in institutions. Some disability rights advocates have wondered whether groups such as VOR and CASH/PCR are merely fronts for the unions and not representative of parents at all.

Even with foes like VOR, pro-community family members are still confident that the battle against California's institutions will be won. "What we have done is almost completely stop new admissions to the Developmental Centers. That's a major step forward," says Bob Little, whose daughter with mental retardation lives in the community. Bob is also a member of People First, a self-advocacy group. "Parents of young children with disabilities no longer think about putting their children in Developmental Centers." The only pro-institution group, he says, are the older parents "who are afraid of what they did fifty years ago. They regret it, and they feel guilty about it. Now they have to face the fact that they made a bad decision about it."

In order for people with disabilities who move out of institutions to be full members of the community, the community must change, says Little. "How do you change the attitudes of communities so people are more welcome when they come? Some of us think we have to go out and sell this idea to the city council, the mayor, let them know there are some changes that are occurring. Things like sheltered workshops are no longer appropriate, and so on. That there needs to be access and transportation. A whole infrastructure that needs to be in place. That there's a need for ADAPT, People First and Senior groups, and they need to work together."

Maybe someone needs to tell that to the California Medical Association. They're one of the groups who passed a resolution for a moratorium. "There's been a lot of reflection in the CMA over the resolution they passed," says Mark Polit, President of the Alameda County Developmental Disabilities Planning and Advisory Council. "They probably realized it was passed with incomplete information, only hearing one side of the story, as well as putting them in the uncomfortable position of suggesting we keep people in Developmental Centers because of lack of adequate medical care in the community. If that is true, they need to not be the cause of inadequate care."

And the resolution passed by the Arc? "A lot of people in the Arc don't even realize they have a moratorium resolution," says Polit. "It was drafted by CASH/PCR members on Arc's board and then presented to the group." He says Arc has "since issued a clarification" but that they're still "divided" over the matter.

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The division exists in part because those fourteen pages of headlines about community-living-gone-bad are true stories. Of course, there are also thousands of true torture tales about life inside institutions, but it is clear that institutions do not hold a monopoly on horror stories.

"The most important things that lead to abuse are when people are isolated from their communities or other people, and when people are put in a position of lack of power, when their caretakers have lots of power over their lives, and when they're taught to obey," says Polit. "Those are the key factors that lead to abuse. Those factors exist disproportionately in institutions." But, he goes on, "There are also some group homes that are isolated, where the caretakers have a disproportionate amount of power."

Abuse can happen both in institutions and in the community. But there's one clear difference, says Polit: It is possible in the community to be free. "Moving people into our communities is about freedom. It's about civil rights. It's about access to enjoyable and stimulating things. None of us would choose to live in an institution."

The argument for or against community has been framed as being between institutions and group homes. But some advocates don't see it that way. Take institutions completely out of the picture, they say; group homes will be the next dinosaur to disappear.

"Most people don't want to live in a group home either," says Wendy Wolfe, an advisor to Bay Area People First. "Like nobody's ever heard of owning your own home, or shared housing. If you think about the possibilities, you can work with your community and create them."

Many advocates are pushing beyond the group home model to supported living, which is very similar to the personal assistance services used by people with physical disabilities.

> *"In order for people with disabilities who move out of institutions to be full members of the community, the community must change . . . there needs to be access and transportation. A whole infrastructure [that] needs to be in place."*

"The person could have an arrangement where they could live on their own," says Wolfe. "They could choose the supports they want. Maybe a neighbor, a best friend, or someone from a service provider. The Supported Living agency is more like a service broker. The consumer would get the in-home services they need. It's happening here in California. A lot of people who are coming out of the institutions are going into supported living. It's more creative."

"We're just getting a toehold on supported living," says Ellen Goldblatt, Senior Attorney for Protection and Advocacy, Inc. of California. "The idea is that people with disabilities control their homes and the service providers come and go, and the level of service goes up and down as people need it. Supported living separates housing from services; you rent your apartment, buy your home, and then get a provider. If the provider changes, you don't have to move."

"We need to get more into supported living," says Bob Little. "We must have the dollars from the institutions flow into the community with the person. In Tennessee, people have control of their own dollars."

"Look at what happened in Oklahoma," says Conroy. "The Hissom Memorial Center closed, and no one was placed in a group home. Everyone went to supported living." They picked where they lived and picked their staff, he said. "If they couldn't, then a strong attempt was made to get unpaid circles of support including family members, neighbors, churchgoers, and so on to help make those choices. In Oklahoma, absolutely the strongest, most positive outcomes were from supported living."

If groups like CASH/PCR, VOR and unions representing the workers inside institutions get their way, thousands of Californians will never get the chance to live on the other side of the wall. The outcome of the battle in California will most likely foreshadow similar battles in other states.

Unfortunately, the message that has been sent across the nation from California is that deinstitutionalization wasn't working. But the message is wrong. It is working, and California disability rights advocates are already eyeing the next battle: getting more consumer-controlled support services, creating a system where the money follows the person, so that person can live the way she wants to live, like every other American.

Josie Byzek works as a Civil Rights Specialist for the Pennsylvania Coalition of Citizens with Disabilities and is a member of ADAPT.

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It is with deep sadness that we announce that our long time friend, Brock Comegys, has passed away. Brock and his wife Addie have been TASH members and partners in the fight for equity and diversity for over fifteen years. We offer our heartfelt thoughts to Addie and the rest of Brock's family. We also express our sincere appreciation to all the TASH members and others who have made donations to TASH in Brock's honor.

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We offer our thanks to the 1997 Inclusion Roundtable moderators, Dorothy Kerzner Lipsky and Alan Gartner of the National Center on Educational Restructuring and Inclusion (NCERI), The Graduate School and University Center, The City University of New York, for their invaluable assistance in summarizing the roundtable proceedings.

1997 TASH Annual Conference: Inclusion Roundtable

Once again, we were honored to convene the Inclusion Roundtable. Presented below are excerpts from the remarks of each of the panel members. They included, in the order in which they spoke: Frank Laski, Immediate Past President, Executive Board, TASH; Liz Healey, Member, Pittsburgh Board of Education and President-elect of the TASH Executive Board; Bill Henderson, Principal, O'Hearn School, Boston Public Schools; Carmen Alvarez, Vice President at Large (Special Education), United Federation of Teachers; Richard Villa, LRE Consultant for the Los Angeles School District, per the Chanda Smith consent decree; and Tom Hehir, Director, Office of Special Education Programs (OSEP), U.S. Department of Education.

In concluding the panel, Alan Gartner dubbed the newly reauthorized IDEA, the Inclusion Development and Expansion Act. He pointed to the language of the Act's "findings," that special education is to be seen not as a place, but rather as a set of supports that can be provided in any setting, including the general education classroom; as well as the Act's requirements that (1) school district's give consideration to factors other than disability that may be affect a student's performance; (2) a general educator must be on the IEP team (if the student is or may be participating in the general education curriculum); (3) a decision to exclude a student from any aspect of academic, extracurricular or nonacademic activities must be justified; (4) the general education curriculum is to be considered the norm for all students; (5) performance goals must be established for students with disabilities, which are to be drawn from the goals expected of students in general, and that measures are to be developed to include all students in these assessments and these results are to be made public; (6) IDEA funds can be used to implement schoolwide improvement plans and can be of more than "incidental" benefits to general education students; (7) parental rights to participate in the development of their child's program are enhanced; (8) IDEA personnel preparation funds may be used to train general education personnel who will be working with students with disabilities; and (9) the states must enact placement-neutral funding arrangements.

> *Special education is to be seen not as a place, but rather as a set of supports that can be provided in any setting, including the general education classroom*

Frank Laski: I think the 1997 Amendments are actually quite revolutionary in terms of what they do for inclusion and, particularly, the requirements and the mandate that regular education teachers participate in the IEP meetings and a few other things. Parents participate in the placement and hopefully we will be able to talk about how we can use those to really move things along.

Liz Healey: Several years ago, maybe 4-5 years ago, we developed an early intervention mosaic program. We were committed to transforming all of the segregated early intervention programs and supporting all of the young children in early intervention who were served within the City of Pittsburgh in places where other kids their ages were. We are now providing early intervention and I think it's up to 156 sites. We did that very deliberately because we knew that their parents would feel that when they graduated from early intervention and went on to school age programs they should continue to be with everyone else. That has created a really healthy tension. We were able to get the Board to adopt a policy in support of inclusion. We had a policy of doing that, but it was hard to change a big system. We have this tremendous leverage where parents want their kids to be there and, yet, I can't say that we are doing a great job with all those kids and all those schools.

Bill Henderson: As the building base administrator, the most glaring impact of the new IDEA re-authorization to me is whether or not the children in my

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building are included or in substandard, separate classrooms. They now have to participate in the same curriculum and same activity. So if third graders are supposed to read the book, "Charlotte's Web," everybody does "Charlotte's Web." If sixth graders are supposed to study world geography, everybody studies it. If fifth graders are doing a unit on bones, everyone does it. If the first, second, and third graders are playing kick ball, everybody does it. If the seventh graders are doing something with the cigarette prevention program, they all do that. And that has some implications because I think by and large for many kids who have been in substantially separate classes, particularly in multiple grade classrooms, the teachers have felt in the past that they did not have to do the whole curriculum, but now we do.

Carmen Alvarez: As a union leader, we are absolutely in favor of appropriate integrated programs. I think most people understand that about the unions. I think the disagreement is to the degree. For us, we do not believe that there should not be a continuum. We do believe that there should be a continuum of service from self-contained to residential to general education with support. We believe in the whole continuum.

However, we have also come a long way and we realize more children should be placed in integrated places in general ed — part of the day or all of the day. That should be increased and it is not about mild to moderate; it could be any disability from severe to whatever. The experts need to be available to the staff. The biggest fear the general ed teachers have in New York City is, here we have 28, 29, 30 kids with a variety of disabilities, and I don't have the expert with me to help me acquire those tools. I think the whole aspect is interesting.

Liz was talking about the professional development. In New York City, the union is extremely involved in creating and moving forward in the least restrictive environment initiative. What we are doing there is crafting time during the day for teachers, general ed, special ed, related services to meet around the children with disabilities. The best way to move children in and out is to talk about them with the parents and whomever to see what's working and what's not. The problem has been there's no time to meet. You can't meet with them at lunch time, you can't force them to come in the morning, you have to put that time in during the day. So through the LRE initiative, we are building time during the day, we are mandating professional development, we are not going to put people in a program or children, because it is really negligent to put children in a program for disabilities without proper training of the staff, so that they can get the outcomes that we all want.

The other thing from IDEA that "is big" is now that the general ed teacher must participate in the IEP conference. What would you need to keep this kid in general ed? I might need a paraeducator, I might need a specialist. If we don't have enough support in General Ed, there is probably going to be a big bump in special ed referrals, because general ed teachers are going to see that they can probably get support in general ed if they have a special ed kid, and that they could get a paraeducator or somebody else in there. We want to create a situation in General Ed where there is support there already. We want the specialist for behavior, we want the specialist for everything else in general ed so there is not a need to refer.

Rich Villa: Now in terms of barriers that I see, one of the major barriers that has been addressed a couple times on this panel has to be inadequate teacher preparation. If we are going to be successful in meeting the needs of children, in those general educational settings we have got to make major changes: increase service and teacher education. Where we begin to give everyone the strategies, the skills they need, to meet the needs of a diverse group of students, and also to have a conceptual understanding that they are not going to just be technically capable of educating one kind of child who carries a particular label. That their good teaching is what it has always been: good teaching.

In addition to that, of course, we have got to have ongoing, meaningful professional development in schools, districts and organizations. Providing in service has to provide quality models of staff development. I see too few places where that is truly apparent. I also think that we in our professional organizations, associations and unions have got to do a better job of instilling within our membership the ethic of ongoing professional development. We tell our students that we want them to be ongoing, lifelong learners. How are we going to model that for them?

Tom Hehir: In relationship to the IDEA 97 Amendments, one of the things that I think is important to understand is through this re-authorization process that the guts of IDEA are the same as the old law. Children continue to be entitled to free appropriate public education in the least restrictive environment. Based on individualized assessment with due process protections and I think that is something that needs to be emphasized. I also think that it is quite extraordinary in many respects that we were able, as a broad community, to get a piece of legislation to this Congress that has so much in it that promotes inclusion of children with disabilities.

I think one of the challenges that we have in this particular instance is making this an all kids issue and one of the things that we get criticized for in regards to this policy is that it is okay in some states, not all states, to expel children who don't have disabilities and not provide services for those children, but you can't do that for disabled kids. It doesn't make any sense for any kid to be disengaged from education. When we were going through the re-authorization process and we were pushing this issue, and this was a bottom line issue, we were joined by such liberal groups as the Chief of Police Association in supporting our position. Increasingly I think people are realizing that it doesn't make any sense to put kids out in the street on any level. One of our challenges is to make many of these issues all kid issues, and to look for ways to do that.

There are a number of things in the re-authorization that I am very pleased

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with: there is a fundamental principal that runs through a number of Amendments in IDEA 97 which, simply put, is that children with disabilities should be learning in school what other children are learning. Schools should be accountable for that learning. This is what I frankly always believed IDEA was about. It wasn't necessarily explicit and when we started proposing language around access to the general curriculum, we had groups within special ed who were saying, "That's not what the law requires."

Special Education should be the vehicle by which children have access to the general curriculum, not an ending of itself. If we look at 22 years of implementing the Act for too many kids, the Act has been access to special ed and not access to education. That is a major change in the thrust of IDEA.

What we have found, and this is changing, and has to change because the law requires it to change, is that more than half of the children with disabilities have been excluded from state-wide assessments — in some states, it is over 90 percent. In other words, if you are in Special Ed, there is an assumption that you can't do it, and you shouldn't be assessed. When the heat went up on educational accountability, the referral for special education went up also. There was a vehicle whereby people could avoid accountability. That doesn't exist anymore. It is illegal to exclude kids from assessments. The law is very specific that appropriate modification has to occur, and for a small number of kids for whom it doesn't make sense (a very small number) to be included in the regular assessment process, there must be an alternative that tracks that as closely as possible. The results must be publicly recorded. Those are major shifts in the legislation.

The IEP must also have an explanation of when you do not educate children with non-disabled peers and again that is supporting the thrust of Inclusion. There are also a number of other things: The regular education teacher participation we think is critically important. From a data perspective, more and more disabled kids are being educated in general education classrooms. That's a trend, a lot of that trend is due to the people in this room as well as this organization.

What we find in the research is that, often particularly, this is true at the high school level more than the elementary level, the general ed teachers receive no support from Special Education. That kids are, for lack of a better term, dumped. It's a real thing and it does happen, we should not just be satisfied with the notion that children are in regular classrooms. This is particularly true for children who have high instance disabilities. Kids who are learning disabled often receive next to no support when they are integrated.

TASH NOMINATIONS

OPPORTUNITIES FOR LEADERSHIP

1998 TASH EXECUTIVE BOARD NOMINATIONS CLOSE MAY 1st

Five of the fifteen voting positions on the TASH Executive Board of Directors will be vacated in December, 1998.

The Elections Committee will accept nominations for new TASH Executive Board Members through May 1st. Any TASH member whose dues are current and who has demonstrated a commitment to disability advocacy is eligible to be nominated.

CRITERIA

Nominees will be considered who meet some or all of the following criteria. Nominees are sought who:

- Are longstanding, active TASH members
- Have been active in a TASH Chapter
- Have made significant contributions toward improving the lives of people with disabilities.
- Are self-advocates or family members
- Have skills to contribute in the areas of fund raising, development, business management or legislative advocacy
- Have demonstrated progressive leadership in the area of disability advocacy

The Elections Committee is committed to building diversity on the Board with regard to gender, race, nationality, and discipline.

NOMINATION PROCESS

Members may nominate themselves or any other eligible individual by submitting a letter to the Elections Committee. To be considered, the letter must contain the following elements:

1. The name, address, daytime telephone number and e-mail address (if available) of the member making the nomination.
2. The name, address, daytime telephone number, and e-mail address (if available) of the individual being nominated.
3. A letter stating the reasons the individual is being nominated including specific reference to the above list of criteria. The letter should be no more than one page in length.

Please note that submission of a nomination does not guarantee placement on the final ballot.

All nominations and support material must be received by May 1, 1998.

Materials may be sent by fax (410-828-6706, attn. Elections Committee, c/o Nancy Weiss), by e-mail (nweiss@tash.org) or mailed to:

TASH Elections Committee • c/o Nancy Weiss
29 West Susquehanna Avenue, Suite 210
Baltimore, MD 21204

The Deinstitutionalization *of* AMERICA

Following are excerpts from a comprehensive study conducted by James W. Conroy, Ph.D. on the outcomes of moving people with developmental disabilities from institutions to communities in the United States. The activities and outcomes tracked in this report occurred between 1975-1997. In the ensuing 22 years, Dr. Conroy and his staff performed face-to-face visits and collected quality of life data from over 33,000 participants during the course of 77,821 visits.

Dr. Conroy is president and founder of The Center for Outcome Analysis, a not-for-profit firm founded in 1985 for the purpose of research and policy analysis in human services, with emphasis on programs that assist and support people with disabilities. From 1975 to 1992, Dr. Conroy was the Director of Research and Program Evaluation at the Institute on Disabilities of Temple University. Dr. Conroy's expertise is in applied research in the human services, including program evaluation, policy analysis, cost effectiveness analysis, and quality assurance systems. Dr. Conroy began doing research in the developmental disabilities area in 1970, and has continued to work in this field since then. He has also performed studies in mental health, aging, child welfare, drug abuse treatment, education, housing, AIDS, immigration, criminology and prisons, and military/defense matters.

Dr. Conroy has served as a consultant to 18 federal agencies, to more than 100 state and local agencies since 1970, and has been the Principal Investigator for 65 governmentally and privately funded grants and contracts. He has written more than 180 publications in the fields of disabilities, aging, child welfare, and other human service fields, including 14 articles in professional journals, 7 book chapters, and 162 formal research reports to government agencies.

Interviews with Dr. Conroy, and references to his work, have appeared in the New York Times, the Wall Street Journal, the Philadelphia Inquirer, the Chicago Tribune, Nightline with Ted Koppel, the ABC Evening News with Peter Jennings, and 60 Minutes with Ed Bradley.

Research Shows Multiple Major Benefits of Community Placement

In the past 20 years, a body of literature has developed on deinstitutionalization of people with developmental disabilities. It shows what happens to the quality of life of people with developmental disabilities when they move from large congregate care settings to community living (Craig & McCarver, 1984; Haney, 1988; Larson & Lakin, 1989 and 1991.) This body of literature is remarkably consistent. Without contradiction, it demonstrates that people are "better off" in most ways when they leave large congregate care settings for community living in small, family-scale homes. Correspondingly, the satisfaction and perceptions of quality among parents and other family members rises.

The measurable benefits from moving to the community can be summarized. The central question of studies of the outcomes of community placement has been: "Are people better off, worse off, or about the same?" The phrase "better off" inherently implies the notion of "quality of life." However, nearly all people have their own complex of factors that they believe contribute to "quality of life." Usually their beliefs are not explicit, but rather, they form an internal set of values and judgments that are not always clearly defined. In this situation, the best available scientific approach is to address as many aspects of "quality of life" as are reliably measurable. Some of the dimensions of "quality of life," or outcomes, that social scientists know how to measure, include:

- independence
- productivity
- integration
- access to the places and rhythms of mainstream life
- access to services when needed
- health
- health care utilization
- health care satisfaction
- mental health
- mental health care utilization and mental health care satisfaction
- friendships
- physical comfort
- privacy
- individualized treatment
- freedom from excessive restraints (physical, chemical, and authoritarian)
- respect for dignity and human rights by staff and others

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- support for choicemaking and learning to make choices
- personal satisfaction with multiple aspects of life
- satisfaction of the family members and "circles of friends" who care about the person
- the overall "locus of control" of the pattern of life (by paid professionals and/or by the person and non-professional relatives, friends, and advocates); power, control, choice, self determination.

When multiple aspects of quality of life, or outcomes, are measured, the results are likely to be "mixed." A given social intervention may improve peoples' lives in some areas, while diminishing them in others, and leaving still other areas unchanged. This is a typical result, for example, in the field of substance abuse treatment programs.

However, the research literature on community versus institutional living has not been mixed. Through the assessment of all of these quality of life dimensions, Dr. Conroy's research in 16 states, and the research of other scientists, has consistently shown strong benefits associated with community placement. Furthermore, the results have been extremely powerful, in that improvements have been documented in nearly every measurable outcome dimension. Research in other nations (Australia, Canada, Denmark, England, France, Ireland, the Netherlands, New Zealand, Norway, Sweden) has revealed remarkably consistent findings associated with institutional closure [Mansell, J., & Ericsson, K. (Eds.), 1996. *Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia, and the USA.* London: Chapman and Hall.]

The following paragraphs contain a brief summarization of the results of some of the largest and longest lasting studies of deinstitutionalization outcomes yet conducted: the Pennhurst Longitudinal Study (Pennsylvania), and the Mansfield Longitudinal Study (Connecticut). These two studies are of special interest because both culminated in total closure of the institution, with nearly all residents moving to community settings. At the end of that section appears a summary of several other large scale studies of community placement processes in California, New Hampshire, New Jersey and Oklahoma. These studies all included analyses of cost effectiveness in addition to the quality of life results.

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> ***Without contradiction, [it] demonstrates that people are "better off" in most ways when they leave large congregate care settings for community living in small, family-scale homes. Correspondingly, the satisfaction and perceptions of quality among parents and other family members rises.***

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Pennhurst Longitudinal Study Results: Pennsylvania

The District Court's order in Halderman v. Pennhurst resulted in the transfer of nearly all of the people living in a large state institution in Pennsylvania to small, supervised community living arrangements (CLAs) in the communities from which they originally came. Since 1978, Dr. Conroy and his colleagues have individually monitored the well-being of each of the plaintiff class members — more than 1,700 persons — every year. Following is a summary of the results of the study through 1992 (the last year in which Dr. Conroy directly supervised the project).

The adaptive behavior growth displayed by people who had moved to CLAs under this court order [was] literally 10 times greater than the growth displayed by people who were still at Pennhurst.

Behavior Change. Average gain in self-care skills upon placement: 9%; 3 years after placement: 12%; and most recent placement (1992): 14%. Average improvement in challenging behavior areas: 1% upon placement; 3% three years after placement; and 6% as of the most recent measurement (1992).

Consumer Satisfaction: The Pennhurst Study included repeated interviews with 56 people who were able to communicate verbally. The number of people reporting satisfaction with aspects of life in the community was approximately double what was found in the institution. There were no areas of decreased satisfaction over the entire course of the study.

Family Satisfaction: At the beginning, 83% of families reported satisfaction with Pennhurst, and 72% opposed movement to the community. However, there was a dramatic change in family attitudes after community placement. In a 1991 community survey of these same families, the results from over 500 responding families concerning their overall satisfaction with community living were: Very Satisfied (65%), Somewhat Satisfied (23%); Neutral (5%); Somewhat Dissatisfied (5%); and Very Dissatisfied (2%).

Amount of Service. People who moved to the community began to receive more hours of developmentally oriented service per month than similar people who stayed at Pennhurst (225 hours per month versus 189 hours per month).

Day Activities. The proportion of people taking part in employment or an active day program increased from about one-third at the beginning of the study to practically 100% at the end of the study in the community.

Costs: The total public cost of serving the people who moved to community living arrangements was significantly less than for the people at Pennhurst (about $110 per day versus $129 per day at Pennhurst). Today, community programs are just as able to obtain Federal Medicaid funds as are institutions, primarily through the Waiver Program.

The five years of the Pennhurst Study led to the conclusion that, on average, the people deinstitutionalized under the Pennhurst court order were better off in practically every way measured. For the people who moved

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from Pennhurst to small community residences, results were conclusive.

Mansfield Longitudinal Study Results: Connecticut

In Connecticut, Dr. Conroy and his associates followed 1,350 class members in CARC v. Thorne, to measure their well-being. At the beginning of the study, most class members were in congregate care settings: state institutions, state regional centers, and private nursing homes. Between 1985 and 1990, approximately 600 persons received community placements under the consent decree.

Approximately 69% of the persons who received community placements under the court order were labeled severely or profoundly retarded, compared to 75% of the CARC class as a whole. This showed that community placement included people with the most significant needs, rather than being restricted to people gifted with high ability levels.

From three separate studies conducted over a 5-year period, the people who moved from institution to community were significantly better off in most of the dimensions that were measured. On the average, class members in CARC who received community living arrangements made significant gains in adaptive behavior after placement in the community. Moreover, people labeled profoundly retarded made the greatest proportional gains: more than 28%.

The study also found that people who had resided in community settings during the entire course of the study had made significant gains in many areas of quality of life dimensions, including: adaptive behavior, challenging behavior, social integration, productivity, earnings, satisfaction, and family satisfaction.

During the course of Dr. Conroy's studies in Connecticut, it was determined that the cost of care at the Mansfield institution rose to $290 per person per day, more than double the cost of services in the community.

Brief Summaries of Other Relevant Outcome Studies and Tracking Projects

New Hampshire: From 1981 onward, Dr. Conroy was involved in studying the process of deinstitutionalization in New Hampshire (Bradley, Conroy, Covert, & Feinstein, 1986; Conroy, Dickson, Wilczynski, Bohanan, & Burley, 1992). In January of 1991, the Laconia State School and Training Center closed. New Hampshire thus became the first state in which no citizen with a developmental disability lived in a state institution.

All of the people who remained at Laconia, a facility with a long and honorable history, are now living in community settings. Most of the last remaining group of people had serious behavioral or medical/health challenges. Up until the final year, many state officials appeared to believe that the institution would always be necessary for some people. In the end, New Hampshire elected to demonstrate the opposite. Even the most "medically fragile" people are now living and thriving in small, homelike settings. This achievement has an important place in the history of developmental disabilities. New Hampshire was the first state to show that communities can support all people, regardless of the severity of their disabilities.

Dr. Conroy is continuing to perform studies and evaluations in New Hampshire.

New Jersey: In New Jersey, the Johnstone Training and Research Center closed in 1992. Dr. Conroy headed a 3 year project to track the former residents and the quality of their lives. Two thirds of the Johnstone people went to other state developmental centers (institutions). One third went to community settings. The conclusions of the research were that both groups had experienced improvements in many dimensions of quality, but the movers to community settings were by far the most improved. Moreover, the care for the people who moved to other institutions wound up costing more than Johnstone, while the care for people who moved to community homes cost less than Johnstone. Dr. Conroy wrote that "Future closure planning should, according to this and past research, employ deinstitutionalization rather than reinstitutionalization as its primary strategy" (Conroy & Seiders, 1994).

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Oklahoma: Since 1990, Dr. Conroy has been working on a statewide quality assurance system in Oklahoma that covers 3,700 people — everyone receiving intensive services in the state. Among these 3,700 people are approximately 1,000 Class Members in the Homeward Bound v. Hissom Memorial Center litigation and consent agreement. In 1995, Dr. Conroy reported that the outcomes for the 520 "Focus Class Members" (those who lived at Hissom on or after May 2, 1985) were in many ways the strongest and most positive he had ever studied (Conroy, 1996). These extraordinarily positive outcomes were associated with a "new" kind of community living arrangement. Nearly all of the Focus Class Members went from Hissom, not into "group homes," but rather into individually designed "supported living" situations. Practically no one had more than two roommates, and most had only one or none. This method of deinstitutionalization turned out to be the most successful. A summary table of the outcome results is shown on page 21.

California: Dr. Conroy is currently heading a project that is tracking the quality of life outcomes experienced by more than 2,400 people in California who have been affected by the Coffelt

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settlement. (See related article on page 10 of this *Newsletter*.) Thus far, the project has resulted in 13 major analyses of the well-being of people who have moved out of California's institutions since the settlement (e.g., Conroy & Seiders 1995a and 1995b, Conroy & Seiders 1996, Conroy 1996). These analyses employed multiple research designs, including pre-post, matched comparison, nonequivalent comparison groups with analysis of covariance, and family surveys. All of this work relied on face to face visits with the people and their caregivers, collecting a battery of reliable measures, plus surveys of every known close relative or guardian.

In all of these studies, Dr. Conroy and his associates found that the movers, as in other studies, have experienced major gains in many measures of quality of life. They also found that community care in California costs a great deal less, even for similar people, than institutional care. The cost analyses include consideration of transportation, day programs, health care, and other relevant "hidden" costs. However, the Conroy group has consistently raised concerns about the overuse of psychotropic drugs, the lack of attention to vocational programs, and the serious underfunding of community programs. They concluded that the Court in California must continue to demand high quality programs.

Family Attitudes Change Dramatically

It is well established that the majority of families of people living in institutional settings are convinced that their relatives are receiving good care, and that they are in the best possible situations for them (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987).

For decades, however, some researchers have openly questioned the strength of parental defense of the institution's quality and appropriateness. Klaber (1969) surveyed parents of people in institutions in Connecticut. He found that more than three-fourths of them were convinced of the excellence of the facilities. As he summarized, "*The parents were convinced of the excellence of the facilities in which their children were placed. The praise lavished on the institutions was so extravagant as to suggest severe distortions of reality in this area.*"

Although parents and other family members approve of the institution, and reject the idea of community movement, these attitudes are not necessarily unalterable. Dr. Conroy first detected the phenomenon of dramatic attitude changes in the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Before community placement, the great majority of families opposed movement of their relatives into CLAs. After community placement, the proportion of families strongly favoring community placement rose dramatically, from less than 20% to over 60%. Similar results were obtained in the Mansfield Longitudinal Study in Connecticut.

Hissom Outcomes Study Summary & Interpretation:

"Are Focus Class Members Better Off Now Than They Were Before?"

Quality Dimension	Answer	Strength of Inference
Adaptive Behavior	Yes	Strong
Choice-Making	Yes	Moderate
Challenging Behavior	Yes	Strong
Productivity	Yes	Strong
Integration	Yes	Strong
Developmental Services	Yes	Moderate
Family Contacts	Yes	Strong
Medications	Yes	Weak
Health Care	No	Weak
Satisfaction	Yes	Strong
Overall Conclusion	Yes	Strong

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During the course of Dr. Conroy's studies in Connecticut, it was determined that the cost of care at the Mansfield institution rose to $290 per person per day, more than double the cost of services in the community.

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Community Living is Not Without Problems, and Requires Protections

One question that continually arises is "What is it about community living that accounts for the clearly established superiority in so many qualities of life?" The reasons why these benefits have so consistently been observed are becoming increasingly clear. The major reason is simply the smaller size of community homes. Dr. Conroy believes that the organizational and economic literatures are completely clear on the conclusion that small group size for daily work and functioning produces higher satisfaction, productivity, and efficiency. This conclusion arises from a multitude of studies of human activity across a variety of settings. The best summary of 100 years of this research was provided by Gooding and Wagner (1985).

Specifically in the field of developmental disabilities, Klaber (1968) was the first to point out the importance of small units for daily living and functioning. Since that time, researchers in developmental disabilities have continually added to the understanding that smaller living units are associated with higher quality of life and better outcomes. Research has also shown that simply "breaking up" institutional wards into smaller "walled off" subunits is emphatically not the same as moving to genuinely smaller homes (Harris, Veit, Allen, & Chinsky, 1974).

For additional information on these studies, contact Dr. James Conroy, The Center for Outcome analysis, at 615-520-2007, or send an e-mail to jconroycoa@aol.com

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Update on MiCASA Hearing

On Thursday, March 12, 1998, advocates came to DC from across the country and gathered on Capital Hill for a public hearing on HR 2020, the Medicaid Community Attendance Services Act (MiCASA). Supporters filled both the large hearing room and an additional large overflow room.

The hearing was before the House Commerce Committee, Subcommittee on Health and the Environment. The bill was introduced by Speaker of the House Newt Gingrich (R) and Minority Leader Dick Gephardt (D) (an uncommon partnership!) and when passed, will allow any eligible person to choose to live in the community rather than live in a nursing home or an institution.

The bill and the hearing were due to the efforts of eight years of work led by members of the national group, ADAPT. ADAPT leader, and TASH Executive Board member, Michael Auberger, was one of ten panelists who testified before the Subcommittee. Mike was joined in support of the bill by Gingrich, Gephardt, presidential Medal of Freedom Honoree and TASH Lifetime Member, Justin Dart, Health Care Finance Administration representatives, and Medicaid Commissioners from Oregon and Kansas. Those two states are running highly successful model Personal Assistance programs using Medicaid dollars. The Subcommittee also heard from Voice of the Retarded representative Polly Spare and Victoria Brown of the National Alliance of the Disabled (a small, relatively unknown group from the Subcommittee Chairperson's district). Spare and Brown have aligned with union and nursing home representatives against passage of the bill.

At a press conference prior to the hearing, Marcie Roth, TASH Director of Governmental Affairs and Public Policy told the large assembled crowd that "TASH will not rest until every American has the opportunity to choose to live in the community." Look for more information about the hearing and the bill in future issues of the *Newsletter*.

QUALITY in Small ICFs/MR *versus* WAIVER HOMES

BY JAMES W. CONROY, PH.D

A recent investigation of California's Waiver program for people with development disabilities, conducted by the Health Care Finance Administration (HCFA), produced harsh critical findings (HCFA, 1997). This piqued our interest, because we have not seen evidence of poor quality among the Coffelt class members who have moved to Waiver settings. We decided to investigate further.

HCFA is responsible for two major funding streams for people with mental retardation and developmental disabilities. One is called the ICF/MR (Intermediate Care Facilities for [people with] Mental Retardation) Program, and the other is called the HCBS Waiver (Home and Community Based Waiver) Program. The ICF/MR program is founded in a medical model of care, and is derived directly from a nursing home and institutional mindset. Waiver programs were introduced in 1981 because of evidence that medical domination of care tended to result in more costly and less person-centered situations. The intention of the Waiver program was to "waive" the extensive and medically oriented standards and inspection requirements linked to the ICF/MR program. Under a Waiver, states could receive Federal financial assistance for individualized, flexible, non-medical, community based supports.

Since the origin of the Waiver program, all scientific evidence has supported the original evidence. **Waiver programs result in cost savings and enhanced quality as compared to ICF/MR programs.** The Waiver regulations required an "Independent Assessment" of the quality and cost-effectiveness of each state's Waiver (section 4442.11 of Medicaid regulations). To date, well over 100 independent assessments have been conducted. There is not a single negative finding. The independent evaluations are maintained in Baltimore at the central office of the Social Security Administration. It would, therefore, seem clear that people can be better served, and at less cost, in flexible, individually designed, non-medically dominated homes.

Nevertheless, HCFA undertook a review of California's Waiver program in 1997. It took almost 6 months to complete. When completed, a total of 91 California citizens had been visited. For a population of 35,000 Californians in the Waiver program, this corresponds to a "margin of error" of plus or minus about 11%. (Political polls generally aim for 5% or lower.) HCFA cited "resource limitations" as the reason that it could not visit a more adequate sample. This contrasted with the fact that the California Waiver has grown from 3,000 to 35,000 people in just four years, and the annual Federal share of the cost is 255 million dollars.

Most important for our Coffelt work was the HCFA claim that their surveyors had found that "Coffelt class consumers showed significant signs of loss of functional ability or health status since being placed in the community." **Since HCFA only visited 91 people, how many of them were Coffelt class members? Of the 35,000 Californians supported under the Waiver program, approximately 1200 are Coffelt class members, or about 3%.** In HCFA's random sample, 3 out of the 91 people visited would be expected (statistically) to be Coffelt class members.

How could any responsible government agency base any kind of claim on visits to 3 people? Indeed, in our opinion, it most certainly should not have done so. To us, this strongly suggested a political agenda rather than a scientific one. **Our visits to thousands of Coffelt class members over the years have supported radically different conclusions than those put forth by HCFA from its visits with approximately 3 people.**

We definitely had to examine the issue further. We decided to compare quality in the Waiver to the small ICF/MR program. The small ICF/MR program has not been criticized by HCFA studies in California, hence it would appear that HCFA finds the ICF/MR program to be acceptable in quality.

If California's Waiver program is so "bad," is the ICF/MR program (HCFA's more favored model of care) any better? This question is perfectly amenable to quantitative investigation. For similar people, are there any differences in quality and/or outcomes between the ICF/MR program and the Waiver program?

At the outset, however, we must recognize that the people served in the ICFs/MR and the Waiver programs are significantly different. ICFs/MR serve people with fewer independence skills and fewer challenging behaviors, and Waiver homes serve people who are more independent but have more challenging behaviors. (We think future investigations should be aimed to find out why this is true — it is certainly not true in ICF/MR and Waiver programs in other states such as Connecticut and Pennsylvania.) Comparisons of quality cannot proceed until these differences are controlled for. The comparisons would be "apples and oranges." The following Table shows the differences between the two overall groups of Coffelt movers.

Differences Between the People Living in ICFs/MR and Waiver Homes

Setting Characteristic	ICF/MR N=447	Waiver N=490	Signif.
Adaptive Behavior	35	59	.001
Challenging Behavior (High Score is Favorable, meaning less challenging behavior)	84	72	.001
Age	39	38	.094 NS

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Quality in Small ICFs/MR versus Waiver Homes

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As the Table on page 23 shows, the ICF/MR participants were significantly lower on adaptive behavior abilities than the Waiver participants. This meant that the ICF/MR participants were much less capable of independent self-care. The ICF/MR participants also displayed significantly less challenging behavior that the Waiver participants. Age was similar for the two groups.

When the groups we want to compare are different, there are at least three methods available to compare "apples to apples." One is the matched comparison method, which we have used in the past (the "twin study" method). Another is purely mathematical corrections for differences in groups (analysis of covariance). A third is what we call the "similar groups" method, in which we select two groups who have similar characteristics. For the present analysis, we have used the similar groups method, partly because in prior reports, we have already used the other two methods, and partly because it is simpler to describe and interpret.

The two similar groups were composed by selecting people with characteristics that were "in between" the ICF/MR and the Waiver groups. The best groups were those whose adaptive behavior scores ranged from 30 to 50, and whose challenging behavior scores ranged from 75 to 90. When this selection was performed, we were left with 49 people in ICFs/MR and 50 people in Waiver homes. The statistical tests showed that the two subgroups were now equivalent on the most important dimensions, as shown in the following table.

Characteristics of Similar Groups Living in ICFs/MR and Waiver Homes

Setting Characteristic	ICF/MR N=49	Waiver N=50	Signif.
Adaptive Behavior	40	41	0.188 NS
Challenging Behavior (High Score is Favorable, meaning less challenging behavior)	81	81	0.567 NS
Age	41	39	0.179 NS

For these similar groups, the important characteristics were not statistically different. Hence, we could proceed to compare qualities of life and service between these two similar groups.

The results of our analyses for a series of outcome measures are shown in the table below.

Quality Comparisons in ICFs/MR and Waiver Homes For Two Groups of Similar Coffelt Class Members

		Average for ICF/MR Residents, N=49	Average for Waiver Residents, N=50	t	Signif.
1.	Integration Scale	1.8	**27**	2.38	.019
2.	Self-Determination Index	23	**32**	2.92	.004
3.	Physical Quality Scale	74	74	.29	NS
4.	Individualized Practices Scale	59	**65**	3.50	.001
5.	Normalization Scale	73	77	1.44	NS
6.	Adaptive Behavior Change During the Past Year	-.48	-.05	.18	NS
7.	Challenging Behavior Change During the Past Year	3.75	**19.78**	3.05	.004
8.	General Health Rating	4.2	4.1	.70	NS
9.	Number of Dentist Visits in Past Year	1.5	1.4	.95	NS
10.	Number of Doctor Visits in Past Year	10.9	17.7	3.82	.001
11.	How Easy Is It To Get Medical Care Rating	4.0	3.5	1.91	NS
12.	Percent of People Taking Psychotropic Medications	**16%**	34%	2.05	.043
13.	Quality of Life Overall Rating "Now"	78.9	**84.1**	2.65	.010
14.	Cost of Residential Program	$43,447	**$32,151**	7.58	.001

The above Table uses **boldface** to show dimensions on which one type of setting or the other came out superior. The Table presents the results of t-tests, which reveal whether the difference between the two groups' averages is statistically significant. One column gives the actual t value, and the last column gives the level of significance. Any significance below .050 is considered significant. Each line in the table is discussed below.

1. **The data from the Integration Scale, which counts the number of outings per week, showed that people in the Waiver homes tended to get out significantly more often than their similar peers in ICFs/MR.**
2. **The Self-Determination Index or Decision Control Inventory (DCI) shows that the Waiver group had significantly more control over making individual choices in their daily lives than the ICF/MR group.**
3. **The ratings of Physical Quality (comfort, cleanliness, attractiveness, personalization, etc.) were equal among both groups.**
4. **The Individualized Practices Scale, which measures the extent to which people are treated as individuals, indicates that the Waiver group found their settings to be significantly more individual oriented than the ICF/MR group.**
5. **On the Normalization Scale, there was no significant difference between the two groups.**
6. **For adaptive behavior, we found that 52 of the 99 people in this analysis had been visited the prior year in their community homes. Hence we were able to compute the amount of skill development or loss for those 52 people over the past year. There was no significant change in either group in either direction.**
7. **The challenging behavior results were quite different. The 3.75 point improvement among the ICF/MR group was not statistically significant (this fact is not shown in the Table). However, the 19.78 point improvement among the Waiver recipients was highly significant, and was significantly different from the ICF/MR group's gain. In this sample, challenging behavior outcomes were sharply superior among Waiver participants.**
8. **The General Health Rating was similar for the two groups, as both Waiver people and ICF/MR people indicated that their General Health was "Good." We interpret this to mean that the two groups enjoyed approximately the same overall level of health.**
9. **The average number of dental visits were about the same for both groups. However, the average number of doctor visits were different, with ICF/MR people averaging 10.9 visits and Waiver people averaging 17.7 visits per year. For people with similar ratings of general health, one must wonder why one group sees doctors nearly twice as often as the other.**

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A TUNE BEYOND US, YET OURSELVES:

Power Sharing Between People with Substantial Disabilities and Their Assistants

BY JOHN O'BRIEN AND CONNIE LYLE O'BRIEN

Two fundamental and related questions challenge leaders who want to design and manage relevant human service organizations for people who need extensive and continuing personal assistance because of significant disability. The first of these questions concerns discovering ways for people with disabilities to take a valued place in the membership and friendship networks that define community. The second question, the focus of this article, concerns creating relationships and supports that offer people the assistance they require in ways that increase their effective control of their lives; power sharing will be the short label for this basic question.

The question of power sharing can't be avoided

Some might argue that the very idea of power sharing is dangerously naive, if it is not disingenuous. There are at least two different foundations for this argument. On one view, paternalism, professionalism, and prejudice deprive people with disabilities of their rights; it is not power sharing that matters but power, period. Disabled people must organize and struggle to take the power that is theirs by right. Those with power will not give it up, those who are oppressed must confront them and seize it. It is pretty to think of power sharing, but it amounts to little more than a New Age mask for the denial of real rights.

On another view, to speak of power sharing, at least as far as people with significant intellectual disabilities are concerned, is a euphemism, amounting to a denial of the reality of disability. Once again the issue is power, period. The strong and able must protect, guide, and oversee the weak and incompetent. If trendiness leads protectors to shirk their duty in the name of choice, vulnerable people will suffer the consequences of abandonment. Again, it is pretty to think of power sharing, but it amounts to little more than a politically correct rationalization for ignoring the obvious incompetence of people with intellectual disabilities.

These apparently divergent arguments mark the boundaries for the discussion of power sharing, a discussion which only has meaning among people who recognize four contemporary truths about disability:

1. People with cognitive and communication disabilities are far more capable of problem solving and decision making than most people have thought.
2. People with significant disabilities cannot take even the most basic human and civil rights for granted.
3. Even the deepest regard for rights does not erase vulnerability and the quandaries of protection.
4. There is a real imbalance of power between people with disabilities and their assistants.

What is power sharing?

Each of these approaches to definition captures a facet of power sharing between people with disabilities and their assistants.

Power sharing can be defined by its effect—people with intellectual disabilities can participate with satisfaction in ordinary activities that reflect and strengthen their individual capacities and gifts because of the active and imaginative collaboration of their assistants.

Power sharing can be defined by its medium—conscious relationships in which people commit themselves to overcoming the barriers that stand in the way of people with disabilities realizing their dreams, especially when these barriers are erected by prejudice and discrimination.

Power sharing can be defined by the means that promote it—assistants make themselves physically and emotionally available to understand, accommodate, and promote the explorations, participation and contribution of people who would otherwise be excluded or marginalized because of the social and physical effects of disability.

Power sharing can be defined by its absence—people with disabilities are not even ignored, others presume that they have nothing to say and no way to say it; their contributions are not even rejected, others presume they have nothing to contribute; they are simply the raw materials for low status daily work and higher status professional control.

Power sharing can be defined by the purpose it serves—community life will be richer, deeper, and stronger when people who have been devalued and excluded are welcomed and included and expected and assisted to contribute to common life. Community life is narrowed, weakened, and wounded when people are exiled, isolated, and dominated because of disability. People with significant disabilities can be community builders, but only if some of the people close to them join, and amplify, their desire to reveal and realize their dreams.

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Power sharing grows with the recognition of inequality

Sharing power grows from an understanding of who has got what kinds of power. Like anyone else, people with disabilities have power commensurate with their position, their possessions, their skills and abilities, their interests, and their gifts. More than most others, people with substantial disabilities are likely to be isolated from positions of power, impoverished, left with underdeveloped skills due to low expectations, denied opportunities to pursue their interests, and ignored as unable to bring important gifts to a community's life.

Enumerating these obvious limits suggests an agenda for shared action to promote justice by increasing the power of people with disabilities:

- open valued roles to people who have been relegated to the margin;
- increase personal income and economic security by decreasing public expenditure on services that congregate and control and re-investing in cash transfers, vouchers, or subsidies;
- heighten expectations and offer intense and relevant opportunities for education;
- reduce barriers to people developing their interests; and
- develop the hospitality of associations that will be strengthened by the gifts of excluded people.

For many people with substantial disabilities who rely on services, shared action depends on staff collaboration. Here, puzzlingly, there often seems to be a power shortage. Commonly, service staff, and even agency or service system managers, present themselves as nearly powerless in the face of heartless managers, stingy politicians, ignorant and unsympathetic citizens, unmotivated and unappreciative clients, punitive regulators, greedy tort lawyers, and domineering parents. This abdication has at least two bad consequences: first, it makes room in the shadows for the misuse of the real power staff and managers have in the lives of the people they assist, and second, it directs attention away from the possibilities for increasing accomplishment by sharing power.

The first step in dealing with the power shortage among staff and managers is to encourage them to analyze the power they exercise in the lives of the people with disabilities who rely on them. People with significant disabilities depend on the ability and willingness of their assistants to work ethically, imaginatively and unobtrusively. A deeper understanding of the power assistants do exercise creates the possibility that they will search for ways to collaborate with the people they assist to change the conditions of inequality that constrain and distort their relationship.

Forming a new kind of organization

Power sharing subverts the logic of existing service organizations which is based on the oversight and control of people with disabilities. Whether this unilateral control is justified on therapeutic grounds or asserted as a necessary form of social control or presented as a key to the happiness of diminished people, its form allows no significant power sharing. Evolving new service forms, based on shared power between people and their assistants, challenges and threatens everyone involved in the design and management of services.

Handling the question of how to design service organizations so that their staff share power with people who have obvious and significant differences in movement, communication, learning, and self control means holding onto something hot enough to melt many of the structures and alliances that make managers' jobs tolerable. Plenty of emotion is bound up in organizational routines and rituals that allow staff and agency sponsors to overlook ignorance of a person's identity; uncertainties about what a person might prefer, conflicts over the prudence of a person's judgment; life directions that call on staff to learn to do new things in new ways; and the suffering imposed by unjust and devaluing social and cultural processes.

No wonder that for years this heat was quenched in safe controversies: When can clients attend the meetings that plan their individual program? If they attend, how will we deal with them if they make unrealistic demands? Which residents will be allowed to set their own bedtimes? How will we motivate consumers to take more responsibility for following their prescribed regimen of treatments? What issues can the self-advocacy committee be allowed to tackle? Will we have a client on the management committee? Though these questions can generate much controversy, they remain safe questions in that none of their answers challenge the structures, ideas, and relationships that form the service.

Lately, some managers have found a new safety zone by diverting the fundamental question of power sharing into issues of what techniques staff will use on people with disabilities within the existing structures. They are pleased to allow professional staff to adopt training and counseling methods aimed at bringing clients systematically toward the goals of "empowerment" or "self-advocacy." They are proud to share their new vision of clients as "customers" and the many variations of "total quality management" techniques they have adopted. They are glad to say that they are "shifting their paradigm."

In the midst of all this comfortable trendiness, a growing number of people have found the courage to hold onto the question of power sharing, and with exciting results. More and more people with significant disabilities have found their voice and called managers and staff into new kinds of relationships, relationships which have encouraged them to leave behind restricting service forms. The heat of power sharing has melted controlling group residences and shaped new forms of supported living and lifesharing. It has melted mindless or feudal occupational routines and shaped new forms of supported employment and

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active concern for career and vocation.

These new containers for service, aimed at support rather than dominance, are in their formative stages. How exactly they will develop, and what more will be required remains to be seen. But the test of their effectiveness, and the means of steering their development, is clear: because of the way assistance is provided, do the people served, and their assistants, become better and better able to collaborate on actions that contribute to a stronger, richer, more diverse community?

This article is based on a longer report available from the Center on Human Policy. For a copy of this article, write to:

Center on Human Policy
ATTN: Rachael Zubal
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280

The preparation of this article was supported in part by the National Resource Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133D50037. No endorsement by the U.S. Department of Education should be inferred. The Center on Human Policy subcontracts with TASH for space in this Newsletter.

Read (or written) any good books, manuals, checklists, or other products that you consider to be invaluable resources lately?

We are updating the TASH resource catalog and invite you to submit for consideration resources (published or unpublished) that meet the following criteria:

1) Important – the material should make a significant and meaningful contribution to the field.

2) Current – Written within the last 2 – 3 years (exceptions may be made for work considered classic or seminal).

3) Values-based – materials must support TASH values of inclusion, diversity, participation, and social justice.

4) Reasonably-priced – so as to allow affordability to all members.

Materials written or produced by TASH members are especially encouraged. All materials will be reviewed by the TASH Publication Committee for approval. If accepted, TASH would negotiate a business arrangement with the author or publisher enabling TASH to distribute the material. If you would like to submit a resource for consideration, please send a copy to:

Denise Marshall
TASH Central Office
29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204

Materials to be considered in the first edition need to be received by June 1, 1998. Any materials received after that date will be considered for future editions. If you have any questions, please contact Denise at 410-828-8274 x103 or dmarsh@tash.org.

1998 Annual TASH Conference

"Creating Futures Together"

SEATTLE, WASHINGTON • DECEMBER 2-5, 1998
Seattle Sheraton and the Washington State Convention Center

— Search for Reviewers —

Each and every proposal that is sent into the TASH central office for consideration is reviewed by a panel of reviewers knowledgeable in that particular topic area. Reviewers are selected under each of the identified TASH Interest and Action Group topic areas.

This year there are several new areas of interest on the Call for Presentations for which we have not yet identified a review panel. If you or a member you know is interested in being nominated to review proposals on any of these topics:

Spirituality • Aging • Creative and Performing Arts
Management • Ethics/Rights

Please contact Denise Marshall at 410-828-8274 x103 or dmarsh@tash.org

The current climate is one of change and restructuring in issues that affect people with disabilities. The TASH Conference has always been a place where the best hearts and minds concerned with disability rights issues gather. This year the conference committee is looking for topics that focus on building alliances, pushing boundaries, and working together to ensure that the changing climate is one that continues to forge the path for truly inclusive communities.

In case you missed it - **The 1998 TASH Call for Presentations is out! Proposals are to be postmarked by March 31st.** To obtain a copy of the application, call the central office at 410-828-8274 or visit the TASH Homepage at www.tash.org.

Quality in Small ICFs/MR versus Waiver Homes

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10. On the item "How Easy is It to Find Medical Care for This Person?" the responses were similar with both groups indicating "Easy." The difference between the ICF/MR average of 4.0 on our 5-point scale and the Waiver group's average of 3.5 was not statistically significant. Hence we conclude that there is no overall difference in the ease or difficulty of obtaining health care in ICFs/MR versus Waiver homes.
11. The percentage of people taking psychotropic medications was significantly different between the two groups. We found that the percentage of Waiver people taking psychotropic medications was double that of the percentage of people in the ICFs/MR. We would generally interpret this as an indication of higher quality in the ICFs/MR; however, the most appropriate interpretation may not be that simple. Even though the groups are now similar in challenging behavior (both groups average 81 points), the Waiver group izained almost 18 @nts in the past year. It is possible that the use of psychotropic medications played an important role in these dramatic improvements among the Waiver recipients. The final word on the appropriateness of these medications will require further research and clinical investigations; the data available to us cannot settle this question.
12. The Overall Quality of Life Rating "Now," which is usually obtained from a third party informant and includes 14 dimensions of quality, showed that people in the Waiver settings were rated as having a significantly higher quality of life than their similar peers in the ICF/MR settings.
13. Finally, we examined the average cost of each placement. Our data source was the DDS reimbursement rates for each type of community home. It is well known that Waiver reimbursement rates are lower than ICF/MR rates. That is usually justified by the fact that the two programs serve very different kinds of people.

However, the present analysis concerns two very similar groups of people. The Waiver costs average only 74% of the ICF/MR costs in this sample. This is a large and significant difference.

These findings are obviously quite different from the conclusions reached by HCFA (1997). Out of 13 important dimensions of quality, Waiver settings were superior on 6, and ICFs/MR were possibly superior on 1. Even that one, use of psychotropic medications, was tempered by the possibility that the medications may have been appropriate and useful, as judged by behavioral outcomes. In any case, the weight of these data clearly favor the Waiver settings in many areas of quality, for comparable people. Finally, the Waiver program's costs are considerably lower than those for ICFs/MR for comparable people. The data show that, for comparable groups of Coffelt class members, Waiver homes tend to yield higher quality, at lower cost, than the ICF/MR model.

For additional information on these studies, contact Dr. James Conroy, The Center for Outcome Analysis, at 615-520-2007, or send an e-mail to jconroycoa@aol.com.

Announcing the 2nd Annual International Conference on Self-Determination

Achieving Individual and Family-Directed Community Supports

July 10-11, 1998 • Minneapolis Hilton and Towers

Co-sponsored by TASH and The National Program Office on Self-Determination, a project of the Robert Wood Johnson Foundation. This exciting two day conference is not to be missed! Join international leaders in the self-determination movement for interactive, in-depth discussion of the hot issues!
SPECIAL DINNER PRESENTATION FEATURING C. EVERETT KOOP, M.D.

Speakers Include:
Allen Bergman • Valerie Bradley • Mike Callahan • Jim Conroy • Robert Gettings • Bob Kafka • Mary Kay Kennedy
Charlie Lakin • David Mank • Deborah McLean • Clint Perrin • Barb Roberts • Joseph Shapiro • Cathy Ficker-Terrill

Additional Invited Speakers Include:
Quincy Abbot • Ruthie Beckwith • Judith Heumann • Brian Salisbury • Michael Smull • Madeleine Will • Bob Williams
Robert Wood Johnson State Project Staff and Advocates

— TENTATIVE AGENDA —

JULY 9, 1998

Pre-Conference Meeting for Robert Wood Johnson State Project Directors and other Invited Guests
8:00 - 4:00 Self-Determination Project Directors Meeting
5:00 - 7:00 Welcome Reception for all Conference Participants

July 10, 1998

8:00-5:00 General Session and Breakouts
6:00-9:00 Dinner Session, with C.Everett Koop, MD as the featured keynote speaker

July 11, 1998

8:00-4:00 General Session
Breakout Sessions and Table Top Exhibits

Look for sessions on these topics:

- Self-Advocacy as a Political Force
- Self-Determination: The International Perspective
- Where the Rubber Hits the Road: 30 States /100 Communities Have Started Their Engines
- The Tennessee Waltz: Self-Advocates Establishing Self-Determination as Public Policy
- Transportation: Using Medicaid to Get from Here to There
Revolution in Employment Through Individual Budgets
- The New Medicaid
- HR 2020: Community Services Attendant Act (MiCASA)
- The Waiting List: Still Waiting
- Culturally Specific Opportunities
- Whose Quality is it Anyway?
- The Role of the Arc
- Substitute Decision Making
- Transition to Adult Life
- Communications
and much more!!!

Hold these dates and start making plans! If you would like to receive registration materials, please call 1-800-482-TASH (8274)

Report on Closure of Johnston DD Center Issued

The New Jersey Institute of Technology (Center for Architecture and Building Science Research) in Newark, New Jersey has issued a report on the life effects of closure of the Johnston Developmental Disabilities Center. The report, titled, "Life After Johnston: Impacts on Consumer Competencies, Behaviors, and Quality of Life," is available from the Institute.

The report details the lives of 225 adults who left the Center upon closure in 1992. The study was conducted at the request of the NJ State Division of Developmental Disabilities.

For more information or to obtain a copy of the report,
contact Dr. Paul Lerman at hall@admin.njit.edu

NATIONAL HOME OF YOUR OWN ALLIANCE

Announces its

National Conference

"Home Ownership:
A Dream, A Challenge, A Reality"

April 26th - 29th, 1998
Hyatt Regency • Bethesda, Maryland

For additional information,
call National Home of Your Own Alliance
at 1-800-220-8770
or to register, contact Independence Now
at 301-587-4164

HELP! Our 1977 JASH Journals are Missing!

Have you been a member since TASH began producing the JASH Journal? If you have JASH issues dating back to 1977, we are in need of the first two issues published (Volume 1, Nos. 1 and 2) to complete the central office archives.

If you have the first two JASHs in your private collection, we'd like to receive copies. Please contact Nancy Weiss at 410-828-8274, ext. 101 or e-mail nweiss@tash.org if you have access to these issues.

The Department of Special Education at the University of Maryland at College Park is recruiting teachers for enrollment in a Master's training program in Secondary Special Education and Transition for Students with Severe Disabilities. Tuition fellowships of 3-6 credits per session are available to part time students and graduate assistantships are available to qualified full time students on a competitive basis.

To obtain an application and information packet, please leave a message with your name, address, and telephone number with Meg Grigal, Transition Project Coordinator, Department of Special Education, University of Maryland, College Park, Maryland 20742 at 301-405-6498 or e-mail a request to: megrigal@wam.umd.edu

For information on line go to:
http://www.inform.umd.edu/EdRes/Colleges/EDUC/.WWW/Depts/EDSP/.programs/grad-masters.html

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The University of Washington Graduate Program trains teachers to serve the needs of pupils with significant disabilities. Emphasis on data-based, systematic instruction referenced to the requirements of natural school and community settings. M.Ed. degree plus initial teacher certification possible. Dr. Felix Billingsley, Area of Special Education, 102 Miller Hall, Box 353600, University of Washington, Seattle, WA 98195, (206) 543-1827, e-mail felixb@u.washington.edu

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Special Education Service Agency

ANCHORAGE, ALASKA

The Special Education Service Agency currently has two vacancies for an Education Specialist in the following areas. For more information about our organization, contact our website at http://www.sesa.org

Education Specialist - Autism Spectrum Disorders: Minimum Qualifications: Master's degree in education with emphasis on learners with autism spectrum disorders or Master's degree in education with emphasis on the learner with moderate/significant disabilities and extensive course work on autism; minimum of three years recent experience working with learners with autism spectrum disorders.

Experience Needed: (1) developing communication-based support strategies; (2) teaching social interaction and play skills; (3) developing programs to enhance communication skills; (4) current knowledge of assistive technology; (5) knowledge of current research and range of educational practices in the field of autism; (6) qualify for Alaska DOE Special Education Type A Certification. Excellent health; ability to travel extensively and independently in rural/remote Alaska; ability to work collaboratively and independently.

Education Specialist – Orthopedic/Other Health Conditions: Minimum Qualifications: Master's degree in education with emphasis on learners with orthopedic and other health conditions or Master's degree in education with emphasis on the learner with moderate/significant disabilities and extensive course work in orthopedic and other health conditions; minimum of three years recent experience working with learner with orthopedic and other health conditions;

Experience Needed: (1) Developing augmentative communication systems; (2) current teaching knowledge using assistive technology; (3) ability to work collaboratively and independently; (4) qualify for Alaska DOE Special Education Type A Certification. Excellent health, ability to travel extensively and independently in rural/remote Alaska.

Preferred Experience: (1) Working with preschool through high school age ranges; (2) working across student ability levels; (3) experience and/or training with students who are medically fragile; (4) experienced and/or training in traumatic brain injury; (5) training professional and/or para-professional educators; (6) inter-agency networking and collaboration.

For more information about employment or to submit a resume and letter of inquiry, please contact:

Ron Jones, Program Administrator
Special Education Service Agency
2217 E. Tudor Road, Suite 1, Anchorage, AK 99507
907-562-7372 • Fax: 907-562-0545
e-mail: rjones@sesa.org

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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- ( ) Self-Advocate
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- ( ) Other

General Membership (individual)	$88
Agency/business/university/college/library/school (allows 3 conference attendees at the member rate)	$200
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship)	$45
Family (group rate)	$136
Lifetime Member	$1000

All dues are $15 higher for members outside the U.S. & Canada. Funds must be submitted in U.S. Dollars.

If you would like to charge your membership, please fill in the necessary information:
( ) Mastercard ( ) Visa ( ) Discover

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( ) I would like to arrange to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH ________________

What, in particular, inspired you to join ________________

What other disability organization do you belong to ________________

If you are applying for a student membership, please provide the following information:

Department ________________

College/University ________________

Student I.D. Number ________________

Anticipated year of completion ________________

( ) Add $15 if you would like to become a member of your local TASH Chapter

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Please notify TASH of your new address.

Please make check payable to: TASH
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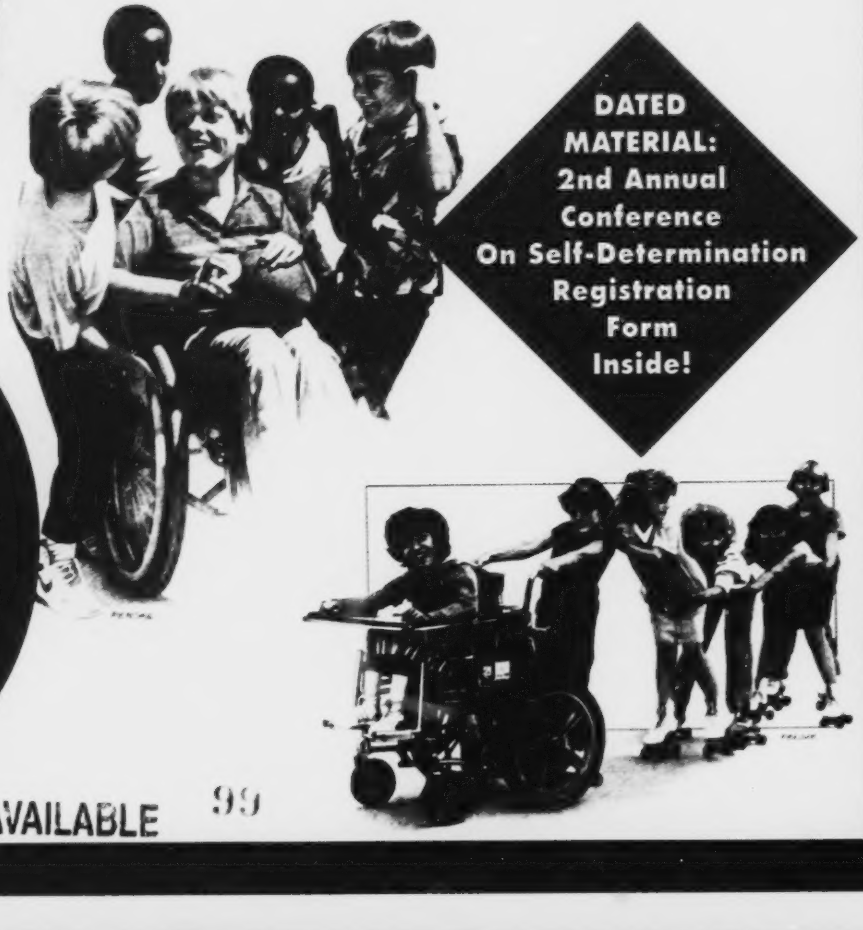
Newsletter

Leisure And Recreation



DATED MATERIAL: 2nd Annual Conference On Self-Determination Registration Form Inside!

ALSO INSIDE: Therapeutic Recreation in the Schools, A Parents' Guide to Quality Inclusive Recreation Activities, and Recreation Human Services Partnerships

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Labels, Terms, Sadness and Hope

BY CANDACE COLE-MCCREA
c.mccrea@tec.nh.us

I remember, as a child, wondering why anyone would send us away, wondering why we were not "good" enough to stay home in families like other children. I know I tried very hard to figure out what "good enough" and "smart enough" were, so maybe I could be that. I never understood what I did when I was home to get sent away again. None of the other kids I knew understood, either. First, I thought it was me. Then I hated them — "the parents." That hatred changed when I was eleven years old.

When I was eleven, I was again hospitalized for almost a year. During that time, a little baby girl was brought in and placed in the bed next to mine. Looking back now, she was around 8 or 9 months old, as near as I can guess. She was put in the bed next to mine because, they said, she was like me (whatever that means). Anyway, every couple of days her parents would visit, and I would sit there and watch them cry over their baby girl, then watch the "white coats" talk them into leaving, then watch the little girl cry for her mother. All of this I had lived through myself, but until then I never saw another person or family live through it in the exact same way. I remember sitting there all day and all night for a couple of days, not eating, just thinking. Then I realized that these people, the "white coats" and the parents, were each trying to do the best they knew how and that they had no real idea of what happened to those of us who were "put away." They really thought it was the best thing, and that maybe that was all they could do. I saw the sadness in the parents and the ignorance in the "white coats."

It was then that my life changed, though it would be another 25 or so years before it changed physically and socially. This little girl, labeled as severely handicapped, who was not able to walk, who was seen as quite retarded, who was told she would spend the rest of her life in institutions and who was being considered for sterilization, decided — I decided — I would somehow grow up and tell them, the parents and the "white coats." I would survive. More than that, I would live, I would get free somehow. I would learn, I would do whatever was necessary to become whatever I had to. Then the time would come and I would speak and write — and I would tell them.

Luckily, thankfully, many others, people like all of you, have taken up this calling as well, and I find that I do not stand alone.

Thank you all for your work and your struggles.

State of Washington Turns the Clock Back on Deinstitutionalization Efforts

BY MARY ROMER, LYLE ROMER AND SUSIE SCHAEFER

More than twenty years ago, Burton Blatt (Blatt, Ozolins & McNally, 1979) said, "We need to empty the institutions. The quicker we accomplish that goal the quicker we will be able to repair the damage done to generations of innocent inmates." To this day, most states across the country are still engaged in efforts to accomplish that goal. Braddock et al (1998) report that from 1980 to 1996 the number of people with developmental disabilities living in state-operated institutions fell by 60.2%. While the overall rate of decline has slowed somewhat during the 4-year period for 1992-1996, it was still at 23%. Thirty-six states have closed, or have scheduled for closure, 114 state-operated institutions by the year 2000. Unfortunately, not all states are following this trend.

With extreme sadness we report that Washington State is one that will, in all likelihood in the foreseeable future, no longer be contributing to the overall reduction of people with disabilities living in institutions. Just last month, Governor Gary Locke signed into law Senate Bill 6751. By law, Washington State "... supports the existence of a complete spectrum of options, including community support services and residential habilitation centers" (institutions). The law guarantees that until the year 2003, the state institutions shall not be reduced below the 1997 capacity (approximately 1,250 people), unless required to do so by the Department of Justice or the governor's budget.

Accompanying this new law is a $2 million appropriation that will be used to offer people not currently receiving residential support the choice to receive their services from community support services or residential habilitation centers. Only those individuals found to require the funding level of support offered by residential habilitation centers will be offered them as a choice for their services. Once the $2 million appropriation is exhausted, choices between community and institutional services will cease. Presumably, at that point, people may only choose the community or the institution, wherever a "vacancy" exists.

It is interesting to note that many people have hailed this law as a great step forward because it allows families, guardians and individuals the chance to make the choice themselves. "Shall I live in the community or in an institution?" This offer is made with the assumption that it is a viable choice between equal alternatives. This ignores, of course, the voluminous evidence supporting community services as affording greater growth in independence, adaptive behaviors, social relationships and the dignity of living in social equality with one's fellow citizens and community members. Offering people the choice to live in isolation from our communities harms not only those individuals, but also our communities.

Does a just and caring society promote and support social policy that is clearly harmful and devaluing to its members? Sadly, sometimes the answer is yes. Witness the long-standing struggles with the tobacco industry and the debate over gun control. Many people would like to see publicity-funded vouchers used to purchase educational services for children in private schools. We constantly struggle with what choices public policy should support and what it should not. Simply offering choice, without regard to the consequences of the choices, is avoiding the real issue. A thoughtful, just and caring society attempts to arrive at a decision about whether specific choices deemed to be harmful ought to be supported through public policy. The propriety of public policy that supports the segregation and exclusion of people with disabilities under the rubric of choice is what this debate should be all about.

We thought we learned, over 40 years ago, that separate is inherently unequal. The actions recently taken in Washington State should serve to remind us that the struggle for disability rights and equality is far from over. As we write this piece there hangs on the wall in front of us a quote from Dante, "The hottest places in hell are reserved for those who, in times of great moral crisis, maintain their neutrality." TASH has never been an organization interested in maintaining its neutrality, yet many in Washington State seem willing to do so on this issue. The Northwest is known for its spectacular beauty and the "niceness" of its citizenry. We are deeply concerned that this desire to not give offense will preclude a much-needed fierce public debate about our State's public policies that support institutions as viable places for some people with disabilities. We need your support. Please continue to stand up and join with us in our struggles.

How can you lend your support?

- Send a letter to your state and federal representatives, along with a copy to the Governor of Washington, denouncing this action and demanding that public policy across the nation not duplicate this travesty by slowing down or ceasing deinstitutionalization efforts that are taking place across the country.

  Contact the Congressional Switchboard at 202-225-3121 to obtain the address and telephone number for your Senate and Congressional representatives. The Governor of Washington, Gary Locke, can be reached via e-mail at governor.locke@governor.wa.gov; by phone at 360-753-6780; or mail: P.O. Box 40002, Olympia, WA 98502-0002.

- Send letters to your local media to counter or offer a different side to the issue and to inform the public that there are alternative opinions.
  If you want to send a copy of your letter to the newspapers in Seattle and Tacoma, here are e-mail addresses for the *Seattle Times*: opinion@seatimes.com and the *Tacoma News Tribune*: leted@p.tribnet.com

- Join us December 3-5, 1998 at the TASH Annual Conference where strands and workshops on self-advocacy, freedom of choice/self-determination, political/legislative action planning, deinstitutionalization, and hundreds of other topics relating to community living, inclusion, disability rights and advocacy will be discussed. Look for details at TASH's web site at www.tash.org

The authors are long-time members of TASH and supporters of self-determination and freedom of choice for ALL people.

Reference

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

Building communities in which no one is segregated and everyone belongs

Forging new alliances that embrace diversity

Advocating for opportunities and rights

Eradicating injustices and inequities

Supporting research and disseminating knowledge and information

Promoting inclusive education

Supporting progressive legislation and litigation, and

Promoting excellence in services

From the Executive Director

BY NANCY WEISS

TASH has lost a long-time friend and a stalwart champion of the rights and humanity of people with disabilities. On Saturday, March 21st, Herb Lovett was killed in a car accident. I first met Herb about ten years ago when I was working for an agency that provided supports to adults with developmental disabilities, who had been discharged from state psychiatric hospitals, and were forging new lives for themselves in their own homes and apartments. It was my role to support the staff who supported this fairly exciting group of individuals and the tough questions sometimes seemed endless. Staff wanted to give people free reign to make choices, but often those choices were detrimental to the point of being life threatening. Together with the people we supported, we struggled with decisions for which there seemed to be no right answer. We invited Herb to spend a few days with us and some of the people we supported and to help us all look at situations with fresh insight.

If Herb was famous for anything, it was fresh insight! By the end of our first visit with Herb we all felt much better. It's OK, he assured us, not to let people destroy themselves. It's OK to offer to remove yourself from someone's life if the kind of support you can offer seems to not be what he/she wants or needs. He also

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Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 1998 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail knelson@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions or advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

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called us on a few points. He understood that everyone had chosen their own homes, apartments, furniture, roommates and jobs – but could it be, he questioned, that everyone had chosen to live in fairly safe-looking neighborhoods, in boring garden apartments? All of us, including the people we supported who had spent time with Herb, learned to view the world somewhat differently through his eyes.

Herb had a wry wit. One evening we were walking through an "interesting" section of Baltimore when we were approached by a panhandler. "Can you spare sixty-eight cents?" the panhandler asked. "Why sixty-eight cents?" we queried. "Oh, it seems to get people's attention" was the response. Herb dug in his pocket and carefully counted out sixty-eight cents which the panhandler accepted with thanks. As he was walking off, Herb called after him, "Don't go spending it on food, now!"

Shortly after leaving the agency at which I had worked for many years, I got a call from Herb. He knew my values had never been a good fit at my previous job and that I had left because I was tired of swimming against the current in an environment in which real change was unlikely. Herb said, "The Executive Director's job at TASH has just become available. You're available. I can't think of a better match." I credit Herb with setting my sights in this direction, a move I'm not sure I would have made without his untiring cheering-on.

Herb fought tirelessly to abolish the use of aversives and was a comrade to me in that battle over the years. He was a loyal e-mail correspondent, frequently telling me that e-mail was invented for hermits like him.

We are dedicating an upcoming issue of the *Newsletter* to Herb and invite any of you to submit your stories, tributes or memories of him.

For a hermit, Herb was loved by a big circle of people. He has left the world a better place. Along with his partner, family, and friends we at TASH will miss him.

Herb Lovett

BY JAN NISBET

Herb Lovett, Ph.D. of Boston, a revered leader, scholar, teacher, and advocate for people with disabilities and their families, and a friend to many died in an automobile accident on Saturday, March 21st. He was 48. His death has brought an outpouring of grief and condolences from around the world.

Born in Boston, Dr. Lovett attended Bowdoin College where he studied classics, Yale University where he studied music theory, Harvard University where he studied education, and the University of Rhode Island where he received a Ph.D. in Clinical Psychology. He worked to promote inclusive supports in and equal access to education, work, housing, and human rights for children and adults with disabilities. He was the co-founder and past president of the Autism National Committee, was a faculty member at the University of New Hampshire, and traveled throughout the United States and the world as a consultant who helped to bring about fundamental changes in the way that people with behavioral difficulties are viewed and treated. In the U.S. he worked with national and state leaders to develop new public policy, legislation, regulation, and practice that outlawed the use of aversive procedures in favor of respectful, decent, and positive supports. He served on the Joint Commission on International Aspects of Mental Retardation of the World Health Organization since 1991; was an Advisor to People First of Ontario, and worked with other self-advocates and family groups around the world. One of Herb's greatest contributions was to listen, give encouragement and recognition to others. He was a lovely blend of intellect and heart, and had the unique gift of being a friend and colleague to many people.

Dr. Lovett waged an intensive battle against the Behavioral Research Institute (BRI), now the Judge Rotenberg Center, to stop the use of punishment and aversive procedures with people who had autism and people with difficult behaviors. His two books entitled *Cognitive Counseling and Persons with Special Needs* (1985), and *Learning to Listen: Positive Approaches and People with Difficult Behavior* (1996) are best sellers and instrumental in the creation of an international movement that advocates for use of positive behavioral supports. His courage and unwillingness to yield to relentless political pressure on these important topics will continue to inspire his colleagues in the field of disability rights.

Herb was also a musician, a writer, and community activist. He lived in South Boston where he opened his and Michael's home—a place filled with music, great books, and his three dogs—to friends, family, and people who needed a place to stay. He is survived by artist Michael Dowling, his partner of 20 years; his godsons John Arico, Joe Feinman, and Matthew Goreham; his nieces Ruth Lovett, and Sarah, Rachel, and Rebecca Goreham; his nephew, Bruce Lovett; his sister Ruth Arico of Sangus; his brother Bruce Lovett of Sabattus, Maine; his parents Ruth and Herb Lovett of Leeds, Maine; the extended Dowling family; and thousands of friends and colleagues who already feel a terrible sense of loss. Herbert Lovett was a kind and wonderful person who will be remembered for his humanity, generosity, humility, and wicked humor.

An Individualized Person-Centered Approach to THERAPEUTIC RECREATION SERVICES

BY ROBERT E. CIPRIANO, ED.D.

The sophistication of therapeutic recreation service delivery is constantly expanding. A person-centered approach draws on an individualized system of planning in which an individual is supported by same-age peers, family members, significant others, and support personnel to design and provide a wealth of recreative opportunities and experiences. Therapeutic recreation can be the synergistic agent to connect an individual with a disability to his/her community.

The person-centered strategies that are employed focus on:

- gathering relevant and meaningful information that addresses strengths, capacities, interests and experiences of individuals;
- developing a vision of what a desirable and fulfilling leisure future looks like; and
- implementing a series of actions, which are coordinated and supported by persons who have a vested interest in, and a commitment to, the individual with a disability.

The person-centered process requires careful planning, active involvement in chronologically age appropriate experiences conducted in generic community based resources, and can best be achieved by a cooperative interagency approach. A major outcome of the person-centered planning process is the formulation of individual support plans to address collective problematic concerns of individuals with disabilities. In such a comprehensive process, the community recreation agency becomes responsible for developing a flexible service delivery model that facilitates and responds to the individual planning process.

> *Individuals with disabilities . . . have the same variety of needs, wants, desires, expectations, and abilities as other people. The only course to full accessibility is programming by abilities rather than disabilities, and then attending to whatever barriers may stand in the way of including any potential participant who has those abilities.*

A developmental and sequential five step person-centered therapeutic recreation model is presented. This model is superimposed upon generic characteristics and key elements of person-centered services.

Individuals with disabilities have the right to be accepted and served in the same way as individuals without disabilities. They have a right to be included in the diversity of humankind. They have the same variety of needs, wants, desires, expectations, and abilities as other people. The only course to full accessibility is programming by abilities rather than disabilities and then attending to whatever barriers may stand in the way of including any potential participant who has those abilities. Individuals with disabilities should be taught to assess their abilities, gain access to recreation programs where they live, work and play, and obtain the myriad benefits of a person-centered recreation program.

When one conceptualizes the term therapeutic recreation and superimposes both the historical perspective of this term, as well as the generic term "recreation," it becomes clear that a new interpretation is needed. All individuals wish to be in control of their destiny. This new focus on self-determination is becoming the engine that fuels the rehabilitation train as we move forward into the 21st Century.

Recreation, with its dominant themes of freedom of choice, individual satisfaction, intrinsic motivation, voluntary participation, and self-reward, should be thought of in new and more encompassing terms. Recreation services for individuals with disabilities can play a major role in enhancing their quality of life. It appears that therapeutic recreation personnel will be called upon to modify their roles in order to meet the diverse needs of individuals with disabilities.

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Therapeutic Recreation Services

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Traditionally therapeutic recreation specialists served as providers of a variety of recreation activities that they planned and implemented for individuals with disabilities. It is logical to assume that in the not-so-distant future, therapeutic recreation specialists will be enablers and facilitators rather than leaders and programmers. They will be knowledgeable concerning the myriad human and facility resources available in the community where individuals with disabilities live, work and recreate. They will facilitate the active participation of people with disabilities by identifying key people to work with each individual to enable that person (i.e., the focus individual) to utilize the generic recreation resources distinct and unique to each local community.

Following is a succinct explanation of the five steps the author has successfully followed in realizing a community-based person-centered recreation program for individuals with disabilities. The five steps that follow emphasize the interaction of individuals with disabilities and their non-disabled peers in natural environments of everyday living.

Step 1: Assess

The assessment process is a systematic, thorough procedure for gathering specific information regarding the focus individual. This procedure is the basis for the Person-Centered Planning Approach. A variety of leisure interest surveys have been developed by the therapeutic recreation discipline. The intent of completing a leisure interest survey with the individual is to ascertain accurately previous recreation experiences participated in by the person, to determine barriers to leisure participation, to obtain a list of significant others, to establish support, etc. This phase identifies the focus individual's recreation needs and interests based upon his or her choices.

Making programs accessible to people with disabilities has both social and practical benefits. It encourages the integration of people with disabilities into the mainstream of society. It also may reduce the need for dedicating resources to special, segregated programs, and can increase participation in regular programs without additional expenses.

Step 2: Explore

The activities the individual has expressed an interest in pursuing in Step 1 are researched. The individual is included in each phase of this exploration. For example, the activities are explored according to their locations, their age appropriateness, the cooperation of the staff, the accessibility of the facility and integration.

Step 3: Plan

The process inherent within person-centered planning is comprised of a number of critical components designed to assure that individuals with disabilities are integrated socially, as well as physically, into the mainstream of society. Thus, meaningful participation in leisure settings demand that attention be paid to various barriers that may prevent the inclusion of persons with disabilities into community-based programs. Attitudes of other staff and participants, age appropriateness, modifications needed, transportation, lack of personnel, building/facility accessibility, contact person and directions must be considered thoroughly and in conjunction with efforts designed to enhance the leisure skill levels of individuals with disabilities.

Step 4: Implement

Actually participate in the activity. Physically go with the participant to the activity. Assist with instruction and adapt the activity to meet the participant's needs, if necessary, allowing the individual to participate as independently as possible.

Step. 5: Evaluate

Evaluations should be both formative and summative. Evaluate subjective and objective data obtained from the focus individual and his/her significant others. Personal, as well as program goals, should be evaluated. Evaluation is an on-going process that helps to ensure productive, appropriate and meaningful experiences for the participant. It is a systematic process of objectively documenting the results and outcomes of the focus individual's experience. Evaluation allows for revisions and improvements to be made regarding the individual's experience.

Making programs accessible to people with disabilities has both social and practical benefits. It encourages the integration of people with disabilities into the mainstream of society. It also may reduce the need for dedicating resources to special, segregated programs, and can increase participation in regular programs without additional expenses.

However, the primary reason for making recreation programs fully accessible is the basic right of all people to be judged according to their capabilities, not their disabilities; their right to be included in all aspects of public life; their right to have fun like everybody else. After all, in the final analysis, isn't this what a recreation experience is really all about?

If you are interested in receiving a copy of the "Person-Centered Planning" materials, please write to the author at Southern Connecticut State University, 501 Crescent Street, New Haven, CT 06515.

1998 Annual TASH Conference

"Creating Futures Together"

December 2, 1998 - Pre-conference Activities and Opening Reception
December 3-5, 1998 TASH Annual Conference

— Conference Update —

The proposals to present at the 1998 TASH Conference are pouring in! We are pleased to announce that TASH has a new staff person to help coordinate the TASH Annual Conference. Overall direction of the conference planning will still be under Denise Marshall. Please join us in welcoming Kelly Nelson, who will be working with Denise to coordinate the processing, review, and scheduling of the conference proposals and sessions. If you have any questions about a proposal submitted, please contact Kelly at 410-828-8274 x105 or knelson@tash.org.

If you missed the deadline to submit a proposal to present at the 1998 TASH Conference, you may still submit an application, however, acceptance will be based on available space and upon the ability to have the proposal reviewed by the appropriate review committee.

— Local Planning Committee Meets in Seattle —

On March 23, 1998, TASH staff traveled to Seattle to meet with local TASH members and others in the Seattle community to begin to plan for the conference. Thanks to the efforts of Mary Romer and Susie Schaefer, we are ecstatic to report that over 45 people were in attendance at the meeting. Attendees brainstormed ways in which they could help with the conference planning, and subcommittees were formed to work on such areas as: Publicity and Promotion; Recruiting Diverse and Multicultural participation in the conference; Providing information on the local area and accessibility; Day Care/Club TASH; Washington Local Issues; and Recruitment and Participation of Local Educators. The group also brainstormed ways in which the presence of the TASH Conference in Seattle could help the local committee. This is a partial list of what they hope to achieve:

- Focus on Community Living and bring in a national perspective on the issue, as well as targeted sessions by speakers of a national stature in light of the recent legislation that has been passed which in essence "reopens the doors of institutions in Washington"
- Generate enthusiasm, support and collective action for full inclusion
- Hold an action during the conference which promotes community living and best practice
- Gain media coverage and education on models for community living and community building
- Focus specifically on secondary education and education reform, since inclusion in secondary schools is an area concern
- Provide latest information on the implementation of IDEA
- Tie the emphasis on Creative and Performing Art for the conference to the exhibit of art which is in the Washington State Convention Center for the month of December
- Have a poetry writing group as part of the conference, and incorporate local writers or performers.
- Have a strand on Employment that will provide practical information for people with disabilities to get jobs
- Focus on housing issues
- Focus on variety of issues in the community, such as faith communities, coalition-building and non-traditional supports
- Promote family attendance through channeling of funds to attend the National TASH Conference

The TASH Conference Committee will be working with the local committee and the TASH Interest and Action Groups to build a conference agenda that supports local, national, and international agendas. Check out the next issue of the *Newsletter* for specific information on keynotes, TASH Tech pre-conference workshops, strands, and potential topics to be seen at the 1998 TASH Conference.

— 1998 TASH Conference Exhibit Hall Information —

The application to participate as a vendor in the 1998 TASH Exhibit Hall is available! The exhibit hall will be buzzing with activity. This is your chance to capture an audience interested in the innovative services, products, and information available to assist people with disabilities. Join us in Seattle December 3 – 5, 1998. For more information or to obtain an Exhibitor Application, contact Rose Holsey, at 410-828-8274 ext. 100; e-mail:rholsey@tash.org

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TASH wishes to acknowledge the generous support of our newest lifetime members

Jackie H. Direen
Karen Moehn

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments. If you are interested in becoming a lifetime member of TASH, contact Rose Holsey at 410-828-8274, ext. 100.

TASH CHAPTER NEWS

Dianna Williams Announces State Senatorial Bid

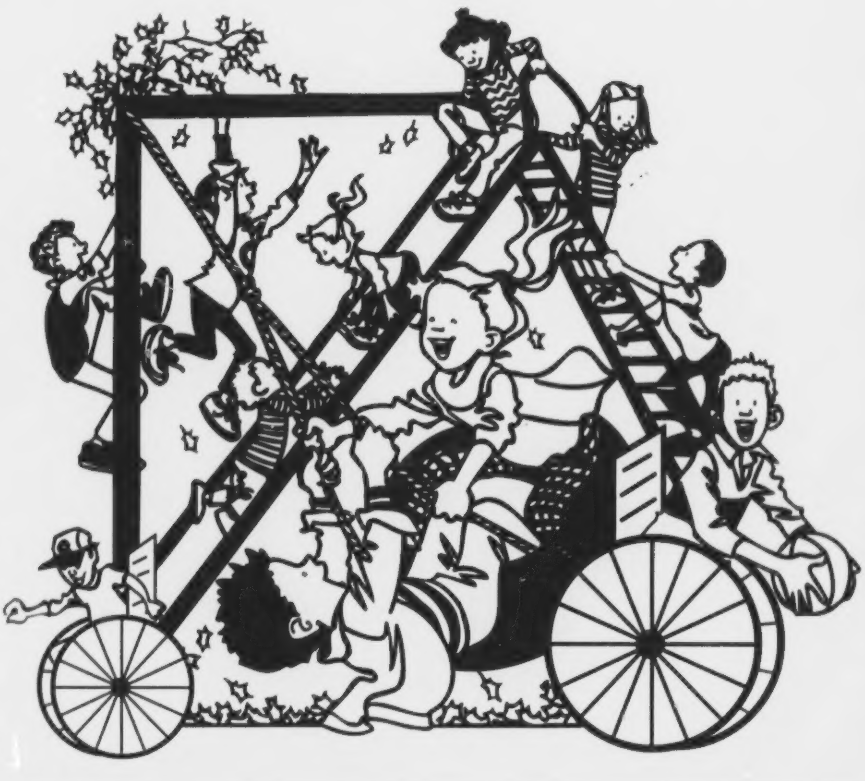
On behalf of the Board of IN-TASH, Michelle Persinger, Co-President of the Indiana Chapter of TASH announces that "one of our own" has declared her intention to run for the State Senate in Indiana. Dianna Williams, IN-TASH's other Co-President, will seek to represent District 38 in the Indiana Senate.

The IN-TASH Board is very proud of Dianna's decision to run and will, of course, support her campaign. Dianna is the parent of a young man with a disability, the Director of Assist, Inc., an employment service provider in Terre Haute, Indiana and a tireless advocate for people with disabilities.

THERAPEUTIC RECREATION IN THE SCHOOLS:

TEACHING STUDENTS TO PLAY

BY LINDA A. HEYNE



Sarah watches a group of children playing on the playground, but is unsure about how to join in the group. Casey's parents wish their son could play by himself for more than five minutes so they can pay attention to their other children and tend to chores around the house. During lunch, Fatima usually sits and eats alone, while her classmates are talking in groups among themselves. Mariah is athletic and coordinated and wants to participate in her school's track and field events. Cooper would like to work out at his neighborhood YMCA but needs someone to show him how to ride the bus and find his way around the building — someone, that is, other than his mom or dad. These situations illustrate just a few of the challenges students with disabilities and their families face related to recreation and play.

Most people agree that having time to recreate and to use one's free time in meaningful ways is essential to a healthy, well-balanced life. Indeed, some people believe that satisfaction with one's leisure participation equals one's overall satisfaction with life. Recreation has been recognized as an important curricular area for students with disabilities for over two decades. And school and community recreation personnel have acknowledged that recreation skills similar to academic and functional life skills require systematic instruction by students with disabilities or they will not be learned (Bullock, Morris, Mahon, & Jones, 1992; Schleien, Meyer, Heyne, & Biel Brandt, 1995; Schleien, Ray, & Green, 1997).

Despite an awareness of the importance of recreation instruction for students with disabilities, few students actually receive leisure education as part of their school program. Relatively few school personnel and parents are familiar with the discipline of therapeutic recreation. Nor are they aware that therapeutic recreation has been authorized as a related educational service in public schools.

Recreation as a Related Service

As early as 1975, with the passage of the Education for All Handicapped Children Act, recreation was identified as a related educational service. This service was reaffirmed in 1997 with the reauthorization of the Individuals with Disabilities Act (IDEA). Similar to the related services of physical therapy, occupational therapy, or speech therapy, a student may also receive therapeutic recreation services as part of his or her Individualized Education Plan (IEP). IDEA identifies four components of recreation as a related service (Aldrich, Powell, & Sable, 1995; Ashton-Schaeffer, 1997; Bullock et al., 1992). These components include:

1. Assessment of Leisure Functioning

A comprehensive assessment of the student's leisure skills, attitudes, interests, and abilities is conducted to assess functional strengths. The assessment provides the basis for developing IEP goals and planning for subsequent instruction.

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Teaching Students To Play

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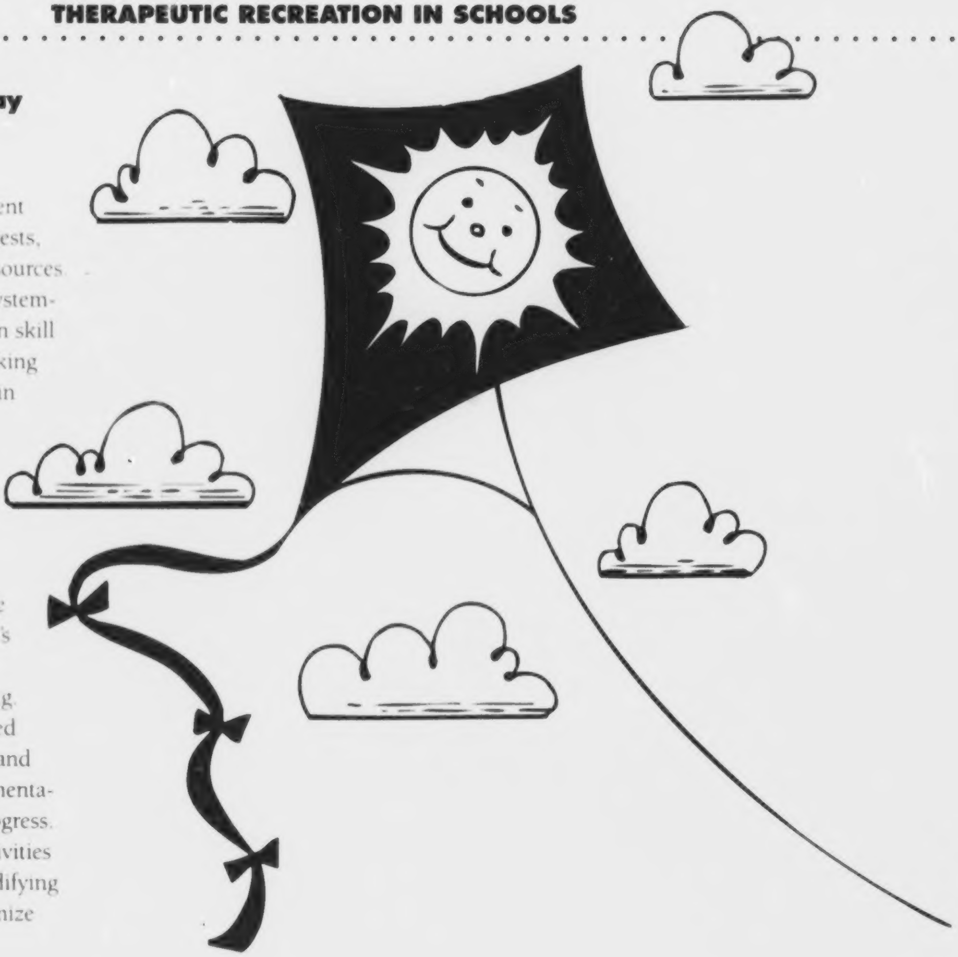

2. Leisure Education

Leisure education builds student awareness of leisure patterns, interests, preferences, opportunities, and resources. Leisure education in the form of systematic instruction enhances recreation skill development, develops choice-making skills, and promotes participation in recreation activities across home, school, and neighborhood settings.

3. Therapeutic Recreation Service

Therapeutic recreation service is designed to enhance the student's social, cognitive, emotional, and physical functioning and well-being. This process includes individualized assessment, development of goals and objectives, implementation, documentation, and evaluation of student progress. This service also includes such activities as environmental analysis and modifying equipment or procedures to maximize participation.

4. Recreation Programs in Schools and Community Agencies

IDEA supports the inclusion of students with disabilities in extra-curricular school activities, neighborhood leisure offerings, and year-round recreational activities. This component is important for all students, and especially relevant for transition age students.

How Students Benefit from Leisure Education

Children and youth with disabilities can experience tremendous growth and learning through the provision of leisure education at schools (Heyne & Schleien, 1996; Schleien et al., 1995). Some of the potential benefits of recreation include:

- Enhanced self-esteem and self-confidence through the successful performance of recreation skills and activities;
- Increased social interaction and friendship skills such as greeting others, making conversation, listening to others, giving feedback, and taking turns;
- Greater feelings of belonging and acceptance in school and neighborhood communities;
- Increased sense of autonomy, independence, self-direction, and the ability to make choices as students make decisions for themselves regarding their recreation participation and friendships; and
- Expanded repertoire of leisure skills, with the potential for lifelong participation across a variety of settings and situations.

In addition to developing specific recreation and social skills, students can develop other important complementary life skills through leisure education. For example, as students learn to access community resources, mobility and transportation skills can be developed. As students interact with others at local parks and recreation settings, communication and interpersonal skills can be practiced and encouraged. Making purchases at stores, restaurants, and other public businesses can strengthen a student's money management skills. Dressing in appropriate attire for such activities as playing tennis, working out, cross country skiing, or going to a dance can motivate the student to learn grooming and dressing skills.

Role of Certified Therapeutic Recreation Specialists in Schools

IDEA has identified Certified Therapeutic Recreation Specialists

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Teaching Students To Play

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(CTRS) as the qualified professionals to provide recreation as a related service. Certified by the National Council for Therapeutic Recreation Certification, CTRSs may either be employed as full-time or part-time staff by school districts or hired on a contractual basis to perform a variety of functions related to leisure education. Some of the roles that a CTRS could perform at a school include:

- Conduct a comprehensive assessment of a student's recreation needs, interests, preferences, abilities, and repertoire in preparation for the development of IEP goals and objectives and the provision of therapeutic recreation services.
- Provide training to parents and classroom teachers about the role of recreation to enhance educational outcomes for students.
- Serve as a "leisure educator" or "leisure coach" to provide direct instruction to students in leisure awareness, social skills, and recreation skills.
- Identify recreation resources and facilities in the community and assist students in accessing them.
- Collaborate with families, school staff, and community recreation professionals to provide leisure education to students and encourage their participation in recreation activities across home, school, and neighborhood settings.

One could locate a qualified CTRS to provide therapeutic recreation services by contacting local universities that train students in therapeutic recreation, parks and recreation departments, rehabilitation and psychiatric hospitals, or community recreation centers.

Including Recreation Goals on the IEP

To ensure that the leisure and recreation needs of students are met, it is important that parents, school personnel, and CTRSs work together to develop recreation and social goals for the IEP. Recalling the scenarios described at the beginning of this article, here are some examples of IEP goals:

- When Sarah wishes to join other children on the playground, she will greet them, interact with them appropriately, and actively engage in the activity.
- When given three choices of a game or toy, Casey will select an activity and play with it independently for 15 minutes.
- During lunch, Fatima will sit with her classmates and engage in conversation.
- Mariah will train for track and field events by participating in regular physical education classes and after-school athletic activities.
- Cooper will ride the bus to the YMCA with a friend once a week to lift weights and jog around the running track.

With careful planning and collaboration among families and professionals, students with disabilities can enjoy the many benefits of an active and gratifying leisure lifestyle through the provision of therapeutic recreation services.

The author, Linda A. Heyne, Ph.D., CTRS, is a Research Associate with the Division of Recreation, Park, and Leisure Studies, Institute on Community Integration. For further information on therapeutic recreation in the schools, contact Linda at 612-625-7816 or send her an e-mail to: heyne001@umn.edu

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Self Advocates Becoming Empowered Supports HR 2020 (MiCASA)

BY LIZ OBERMAYER AND NANCY WARD

The number one goal of Self Advocates Becoming Empowered, which is the national self-advocacy organization, is to close all institutions across the country. We believe that people with disabilities should and can live in the community. Sometimes parents and other people believe that we can't live in the community, but we know this is not true. It has been proven that anybody, no matter what their disability, can live in the community with the right supports.

Because of this goal, we were asked by ADAPT (American Disabled for Attendant Programs Today) to work together to get MiCASA — HR 2020 — passed by Congress. Our goal is to close institutions and ADAPT's goal is to have enough community supports available through attendant programs. MiCASA made sense to us, partly because in Spanish, Mi Casa means "my home."

We believe there is power in numbers, and with numbers you can accomplish more. This was the first time that self-advocates had been asked to support

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Letter From SABE's Self-Advocacy Action Committee

Dear Presidents and Advisors of State Self-Advocacy Organizations,

We, the members of the Advocacy Action Committee of Self-Advocates Becoming Empowered, are writing to ask you to help us to support MiCASA, the Medicaid Community Attendant Services Act of 1997, H.R. 2020.

MiCASA is an important bill that was introduced by Newt Gingrich, Speaker of the House of Representatives. MiCASA would allow people with physical and mental disabilities, old and young, who are eligible for Nursing Home or Intermediate Care Facilities for the Mentally Retarded (ICF/MR) to choose to use those funds for a service called Qualified Community-Based Attendant Services. MiCASA allows people to control how dollars are spent for their services. It allows people to continue to live in their own homes in their communities instead of institutions.

Self Advocates Becoming Empowered, SABE, supports an idea called self-determination. We are working to help all self-advocates have the freedom and choices to control their own lives. MiCASA is very consistent with self-determination.

We have included a handout with this letter about MiCASA to help you understand more about this important bill. Right now, MiCASA is being studied to find out how much it will cost. We hope it will be pushed forward in the next legislative session.

You can help in several ways:

- Write letters from your organization to the four Representatives listed on the attached page. You can call and/or fax them, too.
- Share this information with local chapters, members and supporters of your organization and ask them to write letters.
- Go visit your state representatives and ask them to support and even co-sponsor the bill.
- Join together with other disability groups in your state such as ADAPT.

We believe that self-advocacy is part of a broad disability rights movement. MiCASA is a bill that benefits all people with disabilities. It will give many people a chance to control where they live. It helps people to continue living in their community. It will help free people who want to leave nursing homes and ICF/MRs. Please help us to support this important bill. Working together we can all really make a difference.

Sincerely,

Members of the Self-Advocacy Action Committee:
Keira Williams, Connecticut; Robert Webb, Virginia; Cherie Tessier, Washington; Joe Wrinkle, Missouri; and Liz Obermayer, Massachusetts

SABE SUPPORTS MiCASA

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a national piece of legislation by an organization made up mostly of people with physical disabilities. We were very excited to be asked, because we felt that they saw that we are a strong organization. ADAPT and SABE are very concerned because Voice of the Retarded (VOR) has been opposing this legislation. VOR is made up of parents whose sons and daughters are in institutions. They have been saying that they speak for us. We wanted Congress to know that we are able to think and speak for ourselves, and we are here to prove that.

To work on this, our Advocacy Action Committee wrote a letter (see page 13) that was sent to every state self-advocacy organization. They also wrote a summary of MiCASA (see page 15) so that the membership would be able to make an informed decision on whether they wanted to support it.

Below is a sample letter you can use to show your support for HR 2020. Addresses for Speaker Gingrich and other key legislators are on page 15.

Continued on page 15

— SAMPLE LETTER —

Note: Change this letter to reflect who you are — self-advocate or supporter — and who you are writing it to.

Dear Speaker Gingrich,

(If this applies: Many of us in our group used to live in the state institution, and people thought we could not live in the community. Now we live in our own places, with the help of a lot of people. We want other people to have the same chances we have had.)

Thank you for your support of H.R. 2020, the MiCASA. We hope you will work hard in this next legislative session to get it passed. MiCASA is a very important bill for people with disabilities as it will give many of us and our friends a chance to live in the community and control our own support services. Too many people with disabilities are confined in nursing homes and Intermediate Care Facilities.

We want you to know that Voice of the Retarded does not speak for us or for the people who are still in institutions. We speak for ourselves. Even if we can't talk, we want the same lives as other people have, in the community.

Let's make sure people with disabilities have a choice and the freedom to choose where and how they live, and to control their own supports.

Thanks again for your support.

Sincerely,

Your Name

SABE SUPPORTS MiCASA

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Key People to Send Letters and/or call or fax:

* * *

Speaker Gingrich

Capital Bldg. H-232
Wash. DC 20515-6501
202-225-0600
Fax 202-225-7733

* * *

Minority Leader
Richard Gephardt

Capital Bldg. H-204
Wash. DC 20515-6537
202-225-0100
Fax 202-225-4085

* * *

Commerce Chairperson
Representative Tom Bliley

2409 Rayburn Bldg
Wash., DC 20515
202-225-5755
Fax 202-225-1919

* * *

Commerce Subcommittee
Chairperson
Representative
Michael Bilirakis

2369 Rayburn Bldg
Wash., DC 20515
202-225-5755
Fax 202-225-4085

* * *

Your State Representative

MiCASA (HR 2020) Summary: Key Provisions of the Program

1. Services described here MUST be provided under Medicaid, just as nursing home and other services must be.

2. Services in MiCASA are attendant services (one-on-one staff persons) provided in the home, as needed, by an agency or hired by the person, and are controlled by the person (and if the person wants it, by his/her representatives).

3. Services include back-up and emergency services, training on how to hire, supervise, and fire attendants, and any tasks that the person may need done (including health-related tasks that can be done by unlicensed attendants).

4. If a person is eligible for a nursing home or an ICF/MR (Intermediate Care Facility for the Mentally Retarded), that person can choose instead to use MiCASA funding. The money would follow the person and would be used for the services the person chooses.

5. Services would be based on an assessment of functional need. This means that the person's needs and ability to do things for him/herself would be evaluated to see what services are needed.

6. The money that would go for the nursing home or ICF/MR would be available for the person in the community (would "follow" the person).

7. Services must be provided in the most integrated setting in the community, like in one's own home or family home.

8. The person may be the employer of the attendant or may choose an agency to pay the attendant.

There are some other technical provisions. Please contact ADAPT at 1339 Lamar Sq. Dr. #101, Austin, TX 78704 if you want more information on MiCASA. Their e-mail address is adapt@adapt.org.

ADAPT is also working with the self-advocacy movement by planning to hold a meeting where groups across disabilities will work together. We are still planning the meeting, so we don't have all the details yet. It will probably be in the central region of the U.S. We are very excited to work together on this, because we think that it is important for everyone to have a voice in the work that is done on behalf of people with disabilities. If something is going to affect us, we should be there when it is being planned. We need to be at the table.

If you would like to work with us to pass MiCASA, please write to us at Self Advocates Becoming Empowered, P.O. Box 15162, Loves Park, IL 61132, or contact ADAPT at 1339 Lamar Sq. Dr. #101, Austin, TX 78704 if you want more information on MiCASA. Their e-mail address is adapt@adapt.org.

Yes, She Knows She's Here

BY NICOLA SCHAEFER

Reviewed by Judith Snow

So what's so unusual about a young woman moving out and setting up her own household in the company of four or five friends? Why would her mother write a book about it?

Catherine Schaefer is the subject of Nicola Schaefer's first book, *Does She Know She's There* and now an update, *Yes, She Knows She's Here*. Catherine has forged ahead in living her life — ordinary yet in many extraordinary ways. Catherine does not speak in conventional words, although she is articulate in her own ways. She doesn't move her body much, though she moves people and governments. Catherine has intellectual impairments, yet her compassion and wisdom are legendary.

Through this book we are treated to the groundbreaking work that Catherine, her friends, and family have accomplished in buying an ordinary home and setting up a supportive household. In the late '90's, living in one's own home is still controversial in the world of disability, particularly for an individual who doesn't speak in words and who participates with 24 hour a day support from others. Catherine has been on this path for more than eleven years. Along the way, she has garnered an ever-increasing crowd of close friends, admirers and well-wishers. "Cath" has opened the way for less feisty souls by doing what hadn't yet been done and by continuing to succeed at it in fine style in spite of bureaucratic barriers, her own health challenges and plain old human failings.

Nicola Schaefer is the mother of this daughter who could easily be rejected by everyone, including her own family. Nicola's buoyant words describe a story of innovation and perseverance that led to her daughter having a fulfilling life as a young woman interdependent and participating fully in her own community. Nicola's tale of the trials and the victories is fascinating and important. She teaches us what it takes to turn an avalanche around.

The story of the policy and technical triumphs is important. So is the tale of Catherine's life in her own home. The recounting of the other family members' progress is intriguing. But the best part of *Yes, She Knows She's Here* is the way Catherine's voice sounds throughout.

I have long admired the mystery of communication that people who don't use words often ask us to experience. Frequently we hear that "the nonverbal" have a disability - one that is to be ameliorated with therapy and technology. Yes, Catherine tried all that! What shines through this glorious book is the manner in which Catherine has opened up the minds, hearts and spirit of person after person. Through her attentive silence, her joyous laughter and gestures, and her deep appreciation of life lived in the moment in partnership with other people - through simply being herself - Catherine has brought happiness, healing and opportunity to countless others.

Thank you, Catherine for being the amazing pioneer that you are! Thank you, Nicola, for being the inspiring leader that you are! And thank you for letting Catherine reveal her wisdom and love through your words.

***Yes, She Knows She's Here* is published by Inclusion Press. A special introductory rate of $15 (plus shipping and handling) is available to TASH members. Place your order directly to Inclusion Press by phone (416-658-5363), fax (416-658-5067) or e-mail (74640.1124@compuserve.com)**

How-to Manual

The National Lekotek Center, a nationally recognized leader in making play and recreation activities accessible for children with special needs, has developed Re-Creating Recreation for Inclusion, a how-to manual on achieving accessible recreational programming.

Contact the National Lekotek Center for more information (phone) 847-328-0001; (fax) 847-328-5514. You may also visit their website at <www.lekotek.org>

Do you market or manufacture an assistive device or product that would be of interest to our readers? Why not advertise it in TASH's Assistive Technology *Newsletter*! Scheduled for early Fall '98 release, this issue will present articles on the latest research and innovations in the assistive technology field. Be one of the first to reserve your space in this information and product-packed issue!

For rate information or to reserve space, call Priscilla Newton at
410-828-8274, ext. 102

Through the generous and sustained donations of our members and other interested individuals, TASH is able to bring its members the consistently high level of quality information you have come to expect. Please help us continue this work. Make a donation to TASH today.

TASH is a 501 (c)(3) organization. As such, your donation is tax-deductible. Won't you please take a moment now to complete this donation coupon and send it to us with a check? Donations of any size are greatly appreciated. And while quantities last, if you donate $50 or more, we will rush you a TASH tote bag as a small thank you

Yes, I share TASH's values and want to offer additional support. Enclosed is my check for:

☐ $100 ☐ $75 ☐ $50 ☐ $25 ☐ $10 ☐ Other____________

Name ____

Address ____

City/State/Zip (Postal) Code/Country ______________________

Telephone # ____________________ Fax # ____________________

E-mail address ____________________________________

INCLUSIVE RECREATION:

A Parents' Guide to Quality

BY STUART J. SCHLEIEN AND JOHN E. RYNDERS

"How do we find community recreation programs that will make our child feel welcomed and really part of the group?" This is a question often asked by parents who have a child with a developmental disability. We believe it is important for parents to have a set of questions that they can ask to judge the quality of a community recreation program and its ability to fully include - to welcome, support, and involve - young people with and without disabilities. We have developed one such tool, basing it on our experiences in inclusive recreation over the past 14 years. It is a list of questions that evaluate the characteristics - what we call quality indicators - that reveal the level of commitment to inclusion that exists in a recreation program.

When evaluating a program's quality, we suggest that parents look at four general areas. First, parents should determine how committed the program administration is to inclusion by asking administrators questions related to policies and staffing, and reviewing written materials. Second, parents can tour the program and discuss, both with administrators and staff, logistical and environmental considerations in maintaining an inclusive program. During such a tour parents can also observe and ask questions about a third area, the techniques and methods used to support the inclusion of participants with disabilities within the program. And lastly, parents can observe program activities to see if they address individual needs and preferences. **For each of these areas, there are specific indicators of quality, and questions about their presence or absence will lead to an awareness of whether the fundamentals for inclusion are in place.**

The quality indicators, framed as questions, can be asked not only by parents and care providers, but also by recreation professionals in examining and planning programs aimed at inclusion. The quality indicators provide a tool that can become a permanent part of a program's or organization's self-assessment process. As parents and professionals seek the same goal - quality programs that include young people with and without disabilities - these indicators can help them work as partners in a process that benefits everyone.

■ Quality Indicator #1: Administrative Policy and Practice

In evaluating the commitment of the program to fully including children with developmental disabilities in its recreation activities, the following questions may be asked regarding administrative policies and practices:

- Do the agency's mission statement and profile, as presented in brochures, advertising, and other public relations efforts, reflect a commitment to inclusion?
- Is documentation of previous and current inclusive services available? Are program descriptions and evaluations written clearly and do they reveal social inclusion?
- Are published policies and procedures in compliance with laws pertaining to serving persons with disabilities in settings that are as inclusive and least restrictive as possible?
- Are budget commiments sufficient to support inclusion efforts? Are funds available to adequately provide adaptations, one-to-one assistance, and other supports for those participants with disabilities who need them?
- Are the opinions of parents, advocacy groups, consumer review boards, decision-makers, and other inclusion-oriented persons solicited by the agency? Do they collaborate in inclusion planning efforts, using focus groups and other means to help develop and maintain the integrity of the inclusive program?
- Are staff hired who have backgrounds reflecting individualized programming and experience in inclusion?
- Are generalists and disability specialists committed to the growth of each other's participants? Do their collaborative efforts clearly reflect this co-commitment?
- Are staff given supervision, opportunities for continuing education, and feedback regarding inclusive techniques and practices as part of regular program evaluation and staff support efforts?

■ Quality Indicator #2: Logistical and Environmental Considerations

To examine the ways in which the program procedures, structure, and environment support inclusion, the following questions can be asked:

- Are participants enrolled in programs that are chronologically age-appropriate and that include participants with a range of abilities, including persons without disabilities?
- Do modifications for physical accessibility allow for adaptations for individuals with a variety of needs?
- Are efforts made to keep costs related to adaptations reasonable for the program and the participants?
- Does scheduling reveal sensitivity to times and places that promote accessibility for persons with disabilities, including access to public transportation?
- Are procedures in place to keep key planners and players in continued communication with each other?

■ Quality Indicator #3: Techniques and Methods

Evaluation of the day-to-day operation of the program and what actually happens during the activities can be guided by the following questions:

- Does inclusive programming reflect proven strategies and techniques for successful inclusion? (For more information on strategies for successful inclusion - such as partial participation, companionship training, and task adaptation - parents may want to refer to the book Community Recreation and People with Disabilities: Strategies for Inclusion (2nd Ed.), authored by S. Schleien, T. Ray, and R. Green and published by Paul H. Brookes Publishing Company, 800-638-3775).
- Are there ongoing modifications of activities and materials to accommodate needs of participants, and are the modifications reduced or eliminated when no longer needed?
- Does assessment of skills, experiences, and preferences of participants with disabilities occur as part of the program?
- Do program instructors structure program goals and tasks for cooperative participation?
- Is there an ongoing evaluation of program quality?
- Are staff well-trained in how to conduct the program and given adequate preparation, administrative support, and staff assistance?
- Is there a "welcoming" orientation for participants and families as they are introduced to inclusive programs and adaptive strategies? Are they invited to participate in activities and activity assessment and evaluation?

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A Parents' Guide To Quality

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A child with special needs cannot simply be "dumped" into a recreation activity or program and experience success. Many strategies must be used for a successful inclusive program.

■ Quality Indicator #4: Individualized Programming

In assessing the degree to which the program is individualized to meet the unique needs of each participant, parents can ask the following questions:

- Are the activities based on the needs and preferences of participants?
- Are adaptations geared to the individual? Are they as simple as possible, designed to increase independence within the activity, oriented toward enhancing mastery of recreation and social skills, and planned to be slowly withdrawn when no longer needed?
- Do activities develop skills, leisure knowledge, attitudes, and an awareness of resources that may be used in other settings by the participants?
- Are allowances made for personal challenge and dignity of risk? That is, does the child have an opportunity to experience aspects of an activity or program that may involve a bit of risk or challenge - either physical, cognitive or social - for the child?
- Do activities offer a range of recreation choices, from spectator participation to interactive types of activities?
- Do policies and procedures offer methods to positively and quickly address situations in which participant misunderstanding, behavior, or some other circumstance threatens to disrupt the program or place participants at risk?

Finally, it is necessary to ensure the individualized nature of the program to meet the varied needs of all participants.

■ Future Directions

The inclusion of young people with developmental disabilities in community recreation programs is an essential element in recognizing the inherent dignity of every member of our society. **Successful social inclusion requires that major stakeholders of the service delivery system adopt a philosophy and value system that reflects the right of every individual to participate.** Of central importance is the recognition that all individuals have a valuable contribution to make to their coummunity. **Parents should not be shy about getting involved, realizing that the pressure generated by informed parents and advocates not only gives the system a "push" in an essential way, but supports officials of the system in fulfilling their mission as service providers to the entire community.** It is time for all of us to act together in helping to make a true commitment to all of the communities' citizens. It is time to welcome everyone in community recreation.

Stuart J. Schleien is Professor and Division Head in Recreation, Park, and Leisure Studies, and Senior Researcher with the Research and Training Center on Residential Services and Community Living, University of Minnesota, Minneapolis. He may be reached at 612-625-4073. John E. Rynders is Professor in the Department of Educational Psychology, University of Minnesota, and Senior Researcher with the Research and Training Center. He may be reached at 612-624-5241.

RESOURCES

The following resources may be of use to parents and professionals in planning for inclusive recreation. Please contact the distributors for information about costs and ordering materials.

Friendship and Community Connections Between People With and Without Developmental Disabilities (1993). By A. Amado. A resource for supporting friendships and full community participation through the use of natural social connections. This book explores various dimensions of friendship including work and leisure relationships; gender-related expectations, community associations and groups, and the roles of love, affection, and intimacy. Available from Paul H. Brookes Publishing Company, Baltimore, Maryland - 800-638-3775.

Making Friends: Using Recreation Activities to Promote Friendship Between Children With and Without Disabilities (1993). By L. Heyne, S. Schleien, and L. McAvoy. A handbook that assists parents, community recreation staff, and teachers to support friendships between children with and without disabilities, grades K-6. Discusses what friendships mean for children, barriers to friendship development, and strategies for encouraging friendships through recreation activities and home-school community collaboration. Available from the Institute on Community Integration, University of Minnesota, Minneapolis -612-624-4512.

A Teacher's Guide to Including Students with Disabilities In Regular Physical Education (1994). By M. Block. A practical reference for regular education teachers and adapted physical education specialists to meaningfully include children with disabilities in regular physical education programs. Includes examples, detailed assessment guidelines, suggestions for environmental and activity modifications, and a discussion of inclusion issues and challenges. Available from Paul H. Brookes Publishing Company, Baltimore, Maryland - 800-638-3775.

Powerful Partnerships: Parents and Professionals Building Inclusive Recreation Programs Together (1995). By S. Schleien, J. Rynders, L. Heyne, and C. Tabourne(Eds.). A compilation of writings by 22 authors - including parents and professionals - on the history of inclusive recreation, strategies for enhancing family and community development through inclusive recreation, and successful programs incorporating different inclusive recreation approaches. Available from the Institute on Community Integration, University of Minnesota, Minneapolis -612-624-4512.

Lifelong Leisure Skills and Lifestyles for Persons with Developmental Disabilities (1995). By S. Schleien, L. Meyer, L. Heyne, and Brandt. A resource for parents, teachers, and recreation professionals to help people with disabilities learn essential lifelong leisure skills. Provides guidelines for setting instructional objectives, selecting age-appropriate activities, promoting skill acquisition, adapting activities, encouraging choice-making, collaborating with families, and promoting community recreation participation. Available from Paul H. Brookes Publishing Company, Baltimore, Maryland - 800-638-3775.

Community Recreation and People with Disabilities: Strategies for Inclusion (1996).
By S. Schleien, M. Ray, and R. Green. A step-by-step resource for ensuring the inclusion of people with disabilities in community recreation programs. Chapters address creating inclusive environments, overcoming barriers to inclusive recreation, building bridges between families and agency staff, assessing leisure interests, evaluating environments and accessibility, and designing, implementing, and evaluating recreation programs. Includes a comprehensive annotated bibliography. Available from Paul H. Brookes Publishing Company, Baltimore, Maryland - 800-638-3775.

School-Community Leisure Link: Leisure Education Program Curriculum Guide (1992).
By C. Bullock, L. Morris, M. Mahon, and B. Jones. A leisure education curriculum for elementary through senior high school students that is designed to be implemented across school, family, and community settings. Units include leisure awareness, leisure resources, leisure communication skills, independent decision making, leisure planning, and activity skill instruction. Available from the Center for Recreation and Disabilities Studies, University of North Carolina, Chapel Hill - 919-962-0534.

Project TRAIL Publications
A number of publications are available, including Leisure Education Self-Contained Instructional Packages for People with Cognitive Impairments, a manual for use in creating educational board games that can be used with persons with developmental disabilities in leisure education programs; Community Support Through Leisure Coaching, a guide to ways that family, friends, and community volunteers can assist a person with developmental disabilities in leisure pursuits, and publications on how to develop a detailed leisure education curriculum for persons with developmental disabilities. Available from Project TRAIL, The University of Georgia, Athens - 706-542-5064.

BEST COPY AVAILABLE

As reported in the February TASH Newsletter, many of the Interest & Action Groups met in Boston in conjunction with the annual conference in December. Following is a report on the current initiatives and 1998 agenda items to be addressed by the Community Living, Multicultural, Paraeducator and Special Health Care Needs Interest & Action Groups.

Update on TASH's Interest & Action (I&A) Groups

COMMUNITY LIVING

The Community Living Interest & Action Group listed the following initiatives as its focus activities for 1998:

- Continue to organize and develop the Community Living Strand for the 1998 TASH Annual Conference;
- Continue networking efforts with the Sexual Orientation and the Multicultural Interest & Action groups;
- Support MiCASA legislation through lobbying and letter writing campaigns;
- Continue to advocate for and support the participation of people with labels in both the structure of TASH and the attendance of the annual conference.

Patti Scott and Judith Snow are the Co-Coordinators of the Community Living I&A Group. Patti can be reached at 908-821-8821; Judith's phone number is 416-538-9344 or you can e-mail her at 73742.3523@compuserve.com

MULTICULTURAL INTEREST & ACTION GROUP

The Multicultural Interest & Action Group passed the following resolution regarding U.S. Membership in UNESCO:

That TASH as an organization concerned about the rights and education of all children, actively support renewed U.S. membership in UNESCO.

In endorsing this activity, the following actions will be necessary:

1. A letter from the TASH Board should be written to President Clinton detailing U.S. responsibility in assisting in meeting the special education needs of children in inclusive educational programs throughout the world and offering the assistance and expertise of TASH members.
2. A similar letter to the Speaker of the House of Representatives should also be sent.
3. The letter should then be published in the TASH *Newsletter*, along with notification to members that local chapters and individuals should advise the Senators and Representatives of all states of their support of U.S. membership in UNESCO.

If you would like to assist in the Multicultural Interest & Action group's work on this initiative, or to participate in the group contact Lynda Baumgardner, Coordinator, 307-837-2918.

PARAEDUCATOR INTEREST & ACTION GROUP

Pat Mueller and Anna Lou Pickett will continue as Co-Coordinators of this Interest & Action Group. The Group sees as its critical issue in the next year the need to join forces with other organizations - including advocacy groups, unions, and professional organizations - representing different disciplines, and provider agencies to set guidelines for paraprofessional roles, supervision, training and career advancement.

The Paraeducator Interest & Action Group has committed to provide leadership in the area of development of standards and guidelines through various activities, including Anna Lou Pickett's grant (NRC for Paraprofessionals).

For more information or to participate in the group contact Patricia Mueller, 802-656-8374 or Anna Lou Pickett, 212-642-2948.

SPECIAL HEALTH CARE NEEDS INTEREST & ACTION GROUP

Donna Lehr, Coordinator of this Interest & Action Group, reports that the Group will focus on the issue of integrating specialized medical expertise into inclusive community settings (school, work, resident).

In addition, the Group will organize a strand around this topic during the 1998 TASH Annual Conference in Seattle.

To participate in the Group, of if you are interested in working with the Special Health Care Needs Interest & Action Group on the conference strand, contact Donna Lehr, 617-650-1621.

It's Summer Time! Let's go to camp!

BY CYNTHIA BURKHOUR

Summer camp is a great place for kids to meet new friends, learn exciting "stuff," get bug bites and sun burn, be independent from their parents, challenge themselves, sing songs, play games and have lots of fun! When picking a camp, parents and kids look for the kind of camp experience that will meet their individual interests. Some families look for camps that provide rustic outdoor living in tents, with opportunities to cook meals over an open fire. Some look for specialty camps that focus on cultural, performing or musical arts. There are trip and travel camps, scout camps, "Y" (YMCA or YWCA) camps, church camps, overnight residential camps and day camps run by a wide variety of public and private agencies and organizations to choose from — for most families that is. Some of us don't seem to have the same wide array of options and choices for our children. Our kids' opportunities are sometimes limited to those camps that are willing to accept "those kind of children." You know, those "special" camps out there, somewhere, separate and different, staffed with inordinate numbers of "special" staff, "specially" trained to provide a very "special" camp experience, just for "special" children just like ours.

But what if you and your child just want a typical camp, where kids from your neighborhood, church, or your child's school are going to go this summer? Shouldn't we have all the same choices as any other family? Of course we should. In fact, the Americans with Disabilities Act ensures the rights of children with disabilities to access the same experiences as children who do not have disabilities. **Our children with disabilities can not be denied the opportunity to participate in, or benefit from, programs, services and activities that are available to any other children and they have the right to have those experiences in the most integrated setting possible.**

How do we find a camp that is going to welcome our child who has a disability? We begin by looking for an invitation in the camp literature that tells us that they willingly serve ALL children.

All kids should have the same opportunities for summer fun at camp, together with their friends. Choosing and then registering for camp should be no more involved for our families than anyone else. We shouldn't have to meet some "special" criteria for our family that is different than the eligibility for any other family. Unfortunately, many of us can share our rejection experiences ranging from the "we don't serve those kind of children" excuse to the "wouldn't you rather choose that special camp that knows how to handle special children" or the "fine, if you insist, but we aren't going to do anything to accommodate your child's individual needs" (translation: we'll ensure your child will fail so you won't come back again).

So, how do we find a camp that is going to welcome our child who has a disability? We begin by looking for an invitation in the camp literature that tells us that they willingly serve ALL children. This welcoming statement is sometimes highlighted with the International Symbol of Accessibility that draws our attention to the statement. We should **look for photos or images that show a diverse group of kids having a great time.** Also, look for an opportunity to share information about your child's individual needs for support on the registration form. Sometimes this is just a box to check that indicates you would like to talk to someone about your child's individual support or accommodation needs. Other times there is space on the form to share pertinent information about your child and an invitation to call the camp to discuss personal issues you wish not to include on a general registration form.

Always talk to someone in person! Ask questions about what the camp has to offer. Question the kinds of experience

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It's Summer Time! Let's go to camp!

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the staff have and what kind of experience the camp has including children with disabilities. Find out what their expectations are for camper behavior, participation, knowledge and skills. Share your expectations for your child's experience, as well as your fears and concerns. They need to know what level of physical accessibility your child needs. They need to know what to expect. Be open and honest about your child's strengths and limitations. **Tell them what works best with your child so they are comfortable, safe and happy.** If your child works best with a big picture schedule of the day, then tell them that. Or, if your child functions best with a more detailed "order of life" approach, then teach them how to provide that support.

It is very helpful for parents to meet with the actual program leaders and cabin or group leaders to talk about how the day is planned, so you can give input into potential areas of concern for your child. In addition, the camp will need to have adequate information to prepare your child on what to expect. If your child uses a wheelchair and may need some additional assistance to move around in a large outdoor camp environment, discuss the kinds of support that may be effective. Remember, most camps cover large outdoor open spaces. Many camps are old and do not have many highly developed pathways or buildings. Even though the environment is rustic and may not have paved trails, that doesn't mean your child with mobility limitations can't come and have a great time. What it does mean is that you need to work together with the camp to figure out alternative means of getting around that remove those environmental barriers. **Even when there are environmental barriers like sand, hills, unimproved paths or other obstacles that make getting around difficult, camps still must provide programmatic access through reasonable accommodations, adaptations and supports.**

For example, when our daughter went to camp right after her stroke and while she was still using her wheelchair to get around over large distances, we discussed the issue of how best to combat environmental barriers. We came up with a plan for the camp to borrow a golf cart for the week to help Erin get between activities. They would toss in her wheelchair and she would pick two friends to ride along out to the archery range. They would drive along slowly with the rest of the kids who were walking, so that everyone got there kind of in the same way, except Erin had the cart to move her with the group. Our friends' daughter, Elizabeth, was going to a day camp, so they sent her in her running stroller that was easier to push around out of doors than her wheelchair. Getting our kids around was seen as a solvable little obstacle, not an unremovable barrier once we talked about how it could be done.

In your discussions, look for creative problem solving, a welcoming attitude and a desire to serve your child as a unique individual. All kids are special and have unique needs that should be considered by the camp.

In your discussions, look for creative problem solving, a welcoming attitude and a desire to serve your child as a unique individual. All kids are special and have unique needs that should be considered by the camp.

Develop these open lines of communication and then keep them open throughout the registration process, as well as during and after camp. Make sure the staff feels comfortable contacting you during camp if a situation arises that they aren't sure how to handle. But don't panic if they don't call during camp. Remember, they are trained to work with children through the entire camp experience and may not need any additional input from you, especially if they have been prepared with the most appropriate information. Remember, too, that many camps do not encourage kids to contact their parents during camp to help support the camper's independence. This builds self-esteem and confidence for the campers and the parents.

Openly communicate your evaluation of your child's experience. Camps need to hear about what went well from your perspective, as well as any suggestions you may have for improving future experiences for your child or others. Tell them what made you comfortable, what your child liked best, who did a really effective job working with your child, what accessibility issues may have arisen. The more we talk to each other and make plans to improve the camper experience the better it will be for all campers.

Finally, we need to make sure our kids have the right "stuff" to have a great time at camp. If you don't know what that is, make sure you ask! There is nothing worse than being too hot or cold, wet or sunburned or having sore feet because you don't have the right kind of shoes for the environment. Kids need to have that comfort "stuff," too, like that special teddy bear or book and the all important flashlight with lots of batteries for night time. Kids with disabilities may also need some additional adaptive equipment that may help them to be more independent or successful in the activities of camp life.

Our daughter took along her wheelchair to help get around and her own rocker knife for cutting her food, both of which gave her greater personal independence. When she went on a canoeing and backpacking trip, she took along an adaptive paddle we made for her so she could do her fair share of the paddling. This was really important to her. She wanted to be valued as a contributing participant like everyone else and she wanted to do her share. The paddle she needed didn't exist, so we made it and the kids figured out the rest with some helpful guidance from the adults on the trip. Erin was fully included in all aspects of the experience with some minor adjustments that certainly didn't get in the way of the fun. There were still some activities of the trip

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It's Summer Time!
Let's go to camp!

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that she couldn't do because of her limitations. When they found something she couldn't do, then she bartered support from another camper. She would gather their share of the firewood if they would do her part of the cooking that she wasn't able to. The most important thing for Erin was to be included as an equal partner in the whole camp experience.

Summer camp can be accessible to ALL kids with disabilities together with their friends who do not have disabilities. Camps can include ALL children if we work together. Look for a camp that shares your vision and will realize your dream, then sign 'em up and send 'em off to a wonderful summer adventure!

Inclusive Summer Recreation:

An Alternative to Separate Extended Year Programs

BY CYNTHIA BURKHOUR

Students maintain friendships over the summer through leisure connections with peers in recreation activities. Kids with disabilities need to have these same experiences. The IDEA and the ADA both offer strategies and techniques to help us make it happen for our children. We have the same responsibilities as other parents do to make it happen for our children. We need to sign them up, pay the fee, car pool, take our turn bringing snacks, volunteer for special events, etc., just like all the other parents. The recreation providers have a legal, moral and ethical responsibility to welcome ALL participants and to provide accommodations, adaptations and supports to facilitate participation under the ADA. Under the IDEA, recreation is a related service just like occupational, physical, and speech therapies. Educators have a responsibility to assist students to access leisure and extracurricular activities to maximize the special education experience. As kids are being fully included in typical classrooms, the need for typical social and leisure experiences with classmates outside of the school day is increasing.

Unfortunately, many students receiving special education services who are included in typical classrooms and qualify for extended year services only have separate/center-based summer program options available to them. Their classmates, who do not have disabilities, are participating in summer recreation activities and programs at their neighborhood parks, playgrounds, pools or recreation centers and at camp. These students maintain friendships over the summer through this leisure connection with their peers in summer recreation activities and programs. A tremendous amount of learning happens in these summer experiences that reinforces and demonstrates the application of academic as well as social skills acquired in the classroom. At this time, students with disabilities do not have the same summer opportunities. Typically these students are served in summer school programs just for students requiring extended year services. This effectively segregates them from participation with their classmates, and does not afford them typical learning and social opportunities with their friends. Many students have expressed their displeasure with this "only option" and have said they want to do what their friends do, and not be "sent back," as one girl put it, to a segregated classroom for the summer.

How do we change this scenario and afford kids with disabilities typical summer opportunities while still meeting our responsibility for providing extended year services? Spread the word! Educators, parents and recreation providers need to learn about the concept and the processes utilized to make it happen. They need to learn how to work together to make inclusive summer recreation opportunities a viable alternative to separate/center-based summer school programs. Each has responsibilities for taking the necessary steps to utilize this integrated option.

- ***Educators and families can put recreation, as a related service, on the I.E.P., writing goals and objectives for inclusive summer leisure services, in the community with classmates.***
- ***Schools can utilize educational program funds typically spent on the student in separate extended year services to purchase inclusive leisure services and support services.***
- ***Schools and families can work with recreation programs to provide education and training for the summer recreation program leaders on individual accommodations and support techniques to increase successful inclusion for students with disabilities.***

Wonderful stories are emerging as we begin to include recreation as an integral part of the educational experience. Kids are learning to value each other's contributions and focus on what each *CAN* do in the classroom, on the playground, in the neighborhood and at the park. Kids are learning to enjoy each other's uniqueness and learning how to cooperate and support one another. They are learning about "doing it differently" and still having fun.

Getting our kids involved with recreation opportunities with their classmates is not only the right thing to do, it's a positive thing for all kids. Just think of the wonderful relationships there will be in the future for our children if we help them to become more than classmates, to become friends who share common leisure interests and experiences. These kids of today are the grown-ups of tomorrow. These kids of today will break down the barriers of segregation and will build welcoming communities for everyone.

RECREATION AS A RELATED SERVICE

Recreation is identified in I.D.E.A. as a related service which enhances the educational goals of a child with a disability. If recreation is included in the child's I.E.P., it cannot be completed by a curricular service such as special education or physical education. Recreation as a related service provides assistance, instruction and intervention to enhance and expand the quality of the educational process provided to students with disabilities. Its services can include: assessment of recreation and leisure functioning, leisure education (instruction to improve leisure participation and lifestyle of students with disabilities through leisure attitude, knowledge, and skill development), therapeutic recreation services, and recreation in school and community agencies. Recreation should be provided by a trained Therapeutic Recreation Specialist (TRS) as specified, in I.D.E.A. The actual role of the TRS varies dependent on the actual school in which they are employed. Generally, the TRS serves as a direct service deliverer and/or consultant depending on the needs of the student.

Recreation as a related service is NOT:

- Adapted Physical Education
- recess time for the children
- a duplication of other related services
- used instead of other related services

Recreation as a related service IS:

- significant in its impact on the social and psychological adjustment of an individual
- instrumental in the development of a sense of self-worth and identity of an individual
- essential regarding the ability of an individual to interact with others and their environment
- a functional tool that can be used to achieve social, emotional, and physical objectives identified in the student's I.E.P.
- a vehicle by which the student can experience important aspects of community adjustment, especially in the transition from school to work
- empirically significant in the successful integration of students with disabilities into their community

Recreation as a related service consists of four components.:

1. Assessment of recreation and leisure functioning - procedures to determine current functional strengths in terms of skills, abilities, and attitudes relative to recreation and leisure as the basis for I.E.P. prescription and subsequent remediation.
2. Leisure Education - instruction to improve the leisure participation and leisure lifestyle through the development of positive attitudes toward leisure, the development of skills necessary for recreation participation, knowledge of recreation resources, and recognition of the benefits of recreation involvement.
3. Therapeutic Recreation - the purposive use of recreation activities and experiences to ameliorate deficits in social, cognitive, and physical functioning.
4. Recreation in school and community agencies - the provision of recreation services in the least restrictive environment.

Cindy Burkhour is an Inclusive Recreation Consultant based in Jenison, Michigan and is Coordinator of TASH's Leisure & Recreation Interest & Action Group. For more information on inclusive recreation programs or if you'd like to participate on the Leisure & Recreation I&A Group, contact Cindy at AccessRecreationGroup@juno.com.

Recreation - Human Services Partnerships: The Rural Recreation Integration Project

BY LYNN ANDERSON, CARLA BROWN, AND PATRICIA SOLI

Recreation and leisure are essential in a person's life. This is true whether you are short or tall, young or old, with or without a disability. Recreation is what often draws us into friendships, involves us in our communities, and increases our health and quality of life. However, residing in a community does not necessarily ensure inclusion in its recreation network.

In North Dakota, people with disabilities now reside primarily in local communities, both large and small. This was not always the case. Less than 15 years ago, many people with disabilities lived in institutional settings such as state schools and state hospitals. Following a 1981 lawsuit brought forward by the Arc of North Dakota, large numbers of people with disabilities were "placed" in a variety of less restrictive living environments throughout the state. Through the work of the human service system, communities may have been physically prepared to accept individuals with disabilities by meeting their housing and vocational needs. However, they were not adequately prepared to socially include individuals with disabilities in their communities by meeting their recreation and leisure needs. The recreation/leisure service system, which traditionally provides recreation services to communities, had not been prepared to include people with disabilities in the services it provides. Whether park and recreation departments, YMCAs and YWCAs, sports leagues, church camps, or Girl Scout troops, there was a need in our state to increase the level of awareness and the skills of recreation service providers to be able to include people with disabilities.

In addition, there was limited communication between the human service and leisure service delivery systems. Professionals working in the human service system have expertise in the concerns of people with disabilities and are highly aware of their leisure and social needs, and barriers that people with disabilities encounter. Leisure service providers, on the other hand, have the facilities, resources, and expertise in recreation programming, but often lack awareness of the needs of people with disabilities living in their communities or how to meet those needs.

The Rural Recreation Integration Project (RRIP), a collaborative effort between the North Dakota Parks and Recreation Department and the University of North Dakota, has challenged itself to bridge the gap between these two service delivery systems. Its intent is to develop and help sustain naturally occurring networks where resources and expertise could be shared to most effectively meet the recreation needs of people with disabilities in their communities.

The purpose of the project is to facilitate the physical and social inclusion of people with disabilities into existing community recreation and leisure programs and services. The two primary activities of the RRIP are training and technical assistance. Certified therapeutic recreation specialists have provided training and technical assistance to aid in the development of skills, knowledge, and networks of leisure service providers and human service providers in North

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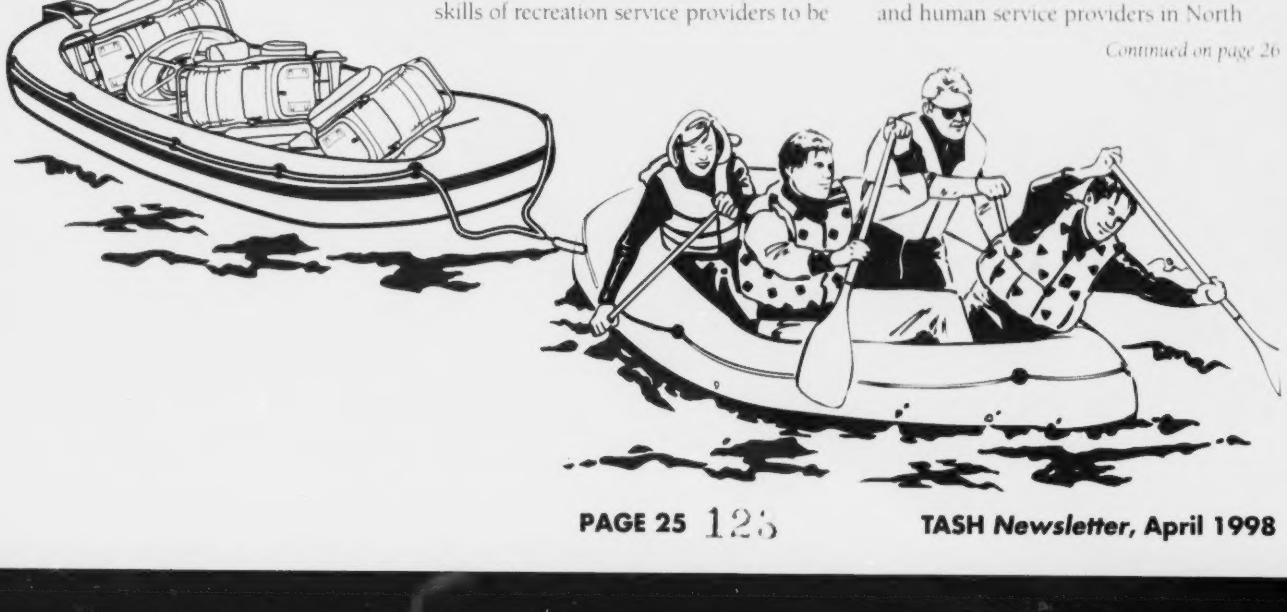


The Rural Recreation Integration Project

Continued from page 25

Dakota as they work to include people with disabilities.

Intensive training was conducted over a three-year period to over 250 people who work in a variety of professional areas in parks and recreation and in human services. Participants in the training included people with disabilities and their family members, park directors, social workers, recreation specialists, group home managers, youth directors, Girl Scout staff, advocacy groups, and others. The training was conducted over a two-month period each year. Because North Dakota is a large, sparsely populated state, we used the North Dakota Interactive Video Network to conduct the training. Through a series of classrooms connected by video technology across the state, people were able to attend the training in or very near their home community. The training focused on disability awareness, physical and program accessibility, and implementation of inclusion in park and recreation programs. During the training, participants formed partnerships composed of a human service provider and a leisure service provider. Examples of partnerships included the following:

- A Girl Scout council and an Arc chapter
- A city park and recreation district and a group home system
- A state park and a disability advocacy group
- YMCA youth sports leagues and a special recreation center
- A park district summer playground program and a parent advocacy group
- A gymnastics club and a school district adaptive physical education program

Together, the partners worked to include at least three people with disabilities in recreation programs. Assignments were completed during the training, but much of the work of implementing inclusion occurred after the training concluded.

Technical assistance was provided by the certified therapeutic recreation specialists to help the partners implement inclusion in their agencies. Technical assistance was as varied as the unique needs each partnership posed. Examples of assistance included the following:

- Staff training on disability awareness and inclusion to YMCA summer camp staff;
- Assistance to a parent advocacy group to plan, implement, and evaluate a friendship/inclusion program;
- Review and revision of a park district's spring/summer schedule and registration form to be more inclusive;
- Disability awareness training to a church youth group;
- Provision of leisure education to people with disabilities living in group homes, with a focus on how to access community recreation services;
- Training for peer advocates in a gymnastics program to facilitate inclusion of children with disabilities;
- Assistance with development of a before- and after-school program that is inclusive of all children;
- Assistance with development of a position for an inclusion coordinator to be shared by four agencies; and
- Accessibility survey and transition plan for Girl Scout camp.

In addition, technical assistance has included the development and use of an adaptive recreation equipment loan library, and provision of staff training, needs assessments, and other supports for agencies. Project staff have worked from an agency level to an individual level, helping children and adults with disabilities and their families be included in the recreation activities of their choice in their communities.

Through the RRIP, we have raised the awareness and skills of recreation providers across the state of North Dakota on how to better serve people with disabilities in their own communities. The 200-plus participants who completed the formal training with the project showed a significant increase in positive attitudes toward people with disabilities and in their knowledge of inclusion strategies. The majority of the training participants implemented inclusion at their agencies, working in partnerships to better utilize expertise and resources.

Mary Jo's story is just one example of the impact the project has had on individual's life (see article on page 27). In addition, some systems change is beginning to occur. For example, most larger park districts across the state have revised their mission statements, agency literature, and registration processes to be more inclusive and welcoming to people with disabilities. Some communities have formed access advisory groups to work on community recreation issues. Partnerships have been formed between disability advocacy groups and park groups.

The Rural Recreation Integration Project can be thought of as a pebble thrown in the water, with ripples spreading across the state. The project has raised awareness and increased opportunities for people with disabilities to be a part of inclusive recreation services. The challenge now is to keep those ripples moving.

Lynn Anderson is Associate Professor with the Department of Health, Physical Education and Recreation, University of North Dakota, Grand Forks. Carla Brown and Patricia Soli are Recreation Specialists with the North Dakota Parks and Recreation Department, Grand Forks and Bismarck, respectively.

For more information on the RRIP, contact Lynn Anderson at 701-777-2978.

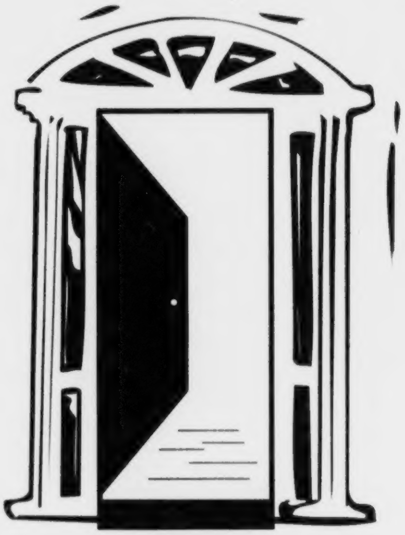
NOTE: The Rural Recreation Integration Project is partially funded by Award #H128J30112 from the Office of Special Education and Rehabilitative Services, U.S. Department of Education.

The Doors Are Opening: Mary Jo's Story

BY VIRGINIA ESSLINGER

As I drove up to the school door, Mary Jo said, "I go by myself; you stay here!" I inquired, "Do you remember where the meeting room is?" to which she replied an emphatic "YES!" So I remained in the car as my vivacious, dark-haired, dark-eyed, 11-year-old daughter, who happens to have Down syndrome, bounded out of the car and closed the door. As she was getting out of the car, three of her fellow Girl Scout troop members were getting out of their cars and coming toward the school door. I heard, "Hi, Mary Jo," and "I like your new glasses." I watched as they all walked in together and headed to the Junior Girl Scout meeting.

Every parent wants his or her child to be involved and socially accepted. Those of us who parent children with disabilities want this for our children as much, if not more, than parents of children without disabilities. Sometimes, for our children, it doesn't come easily. When Mary Jo first joined a Brownie troop, she was fortunate to have a troop leader who was very matter-of-fact and accepting of the fact that Mary Jo had Down syndrome. Mary Jo truly loved being a part of a Brownie troop, so when she was too old for Brownies, she "flew up" to Junior Girl Scouts. There was not a troop at her grade level in her neighborhood school where she is fully included in a regular classroom, so she was assigned to a troop in a neighboring school. The leaders were accepting of her; however, at times they seemed a bit tentative about dealing with her. Then one evening, a member of the Rural Recreation Integration Project (RRIP) spoke to all of the Girl Scout leaders. The next day, one of the leader of Mary Jo's troop told me about what they had heard and how helpful the information she provided had been to them. Both leaders now actively find ways to make sure that Mary Jo is fully included in all activities of the troop and seem much more comfortable with her. This is important, I believe, as **the girls in the troop will take their cue from the leaders. If the leaders model acceptance and ways of including Mary Jo, the girls will learn from them and act accordingly.**



We know we will not always be around to advocate for her. Her friends and the community will have to help with that by having inclusion as an integral part of life. The RRIP has enhanced that process, and in some cases, begun that process. The doors are opening and Mary Jo wants to go through them with her friends.

The girls seem to accept Mary Jo as a member of the troop. They always greet her, include her in games and activities, and assist her when she needs (and will accept) help. Mary Jo truly enjoys being a part of the Girl Scout troop. She always remembers the meetings and is excited about going. **She is learning to interact socially with children outside of her own school, is learning the discipline provided in the Girl Scout program, and is learning all kinds of other things from speakers and activities.**

One evening last year, we received a call from Mary Jo's gym teacher at her school. The teacher said that they were just finishing a unit on gymnastics and she noticed that Mary Jo had really enjoyed it and seemed to do quite well, given her gross motor delays. She suggested that we consider enrolling her in a gymnastics club to continue with gymnastics. She met us at the gymnastics club and introduced us to the coordinator. They explained that they both had been taking classes provided by the RRIP and were looking for children with disabilities to enroll in gymnastics. Mary Jo has been involved in gymnastics continuously ever since. She has made gains in motor ability, balance, coordination, and self-discipline, and has met many other children from around the city. We believe that her gymnastics experience contributed to her ability to finally learn to ride her bicycle without training wheels. The most important factor is that she truly enjoys gymnastics. She looks forward to going and participates fully with the other children in her classes. Had it not been for her gym teacher participating in the RRIP, Mary Jo may have missed this wonderful opportunity.

There is no question in our minds that the RRIP has had a positive impact on Mary Jo's life. **Although she has Down syndrome, she has goals and dreams just like other children. Her goals include living as independently as possible in this community, and doing all the things that other people do, like working, having friends, and having fun.** The relationships she is forming and the relationship skills she is learning through recreational activities are very precious and important to her and to us. We know we will not always be around to advocate for her. Her friends and the community will have to help with that by having inclusion as an integral part of life. The RRIP has enhanced that process, and in some cases, begun that process. The doors are opening and Mary Jo wants to go through them with her friends.

Contributed by Virginia Esslinger, Mary Jo's mother. The family lives in Grand Forks, North Dakota.

The Second Annual National Conference on Self-Determination

Minneapolis Hilton and Towers ❖ July 10-11, 1998

The Second Annual National Conference on Self-Determination, ***sponsored by The National Program Office on Self-Determination, a project of The Robert Wood Johnson Foundation***, will feature two full conference days with in-depth presentations and discussions around the issues critical to making the concept of self-determination a reality. Self-determination refers to a range of efforts aimed at assisting people with disabilities and their families to choose what supports they receive, determine how they live and work in the community, and control their own funds for supports. Participants will have the opportunity to interact with international leaders in the self-determination movement through an extraordinary range of plenary sessions, workshops, discussion forums, luncheon and dinner presentations, poster sessions and informal networking opportunities.

Featured Speakers will include:

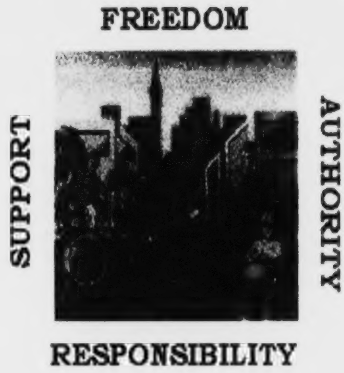
C. Everett Koop, *Former Surgeon General of the United States and Chair of the Advisory Committee for the National Self-Determination Project.*

Joseph Shapiro, *Senior Writer for U.S. News and World Report, and author of "No Pity," a history of the disability rights movement. Mr. Shapiro is currently working on a new book on the future of long-term care in America.*

Quincy Abbot, *President of the Arc of the United States and a member of the Advisory Committee for the National Self-Determination Project.*

Allan Bergman, *Director of State-Federal Relations, United Cerebral Palsy Associations, Inc.*

Valerie Bradley, *Human Services Research Institute, Massachusetts*



Michael Callahan, *Marc Gold and Associates and United Cerebral Palsy Associations, Inc., Mississippi*

James Conroy, *The Center for Outcome Analysis, Pennsylvania*

Cathy Ficker-Terrill, *Vice-President of Quality and Strategic Planning, Ray Graham Association for People with Disabilities and President of the American Association on Mental Retardation*

Chester Finn, *Immediate Past President, Self-Advocacy Association of New York State*

Robert Gettings, *Executive Director, National Association of State Directors of Developmental Disabilities Services and a member of the Advisory Committee for the National Self-Determination Project*

Robert Kafka, *founding member of ADAPT, Texas*

David Mank, *Institute for the Study of Developmental Disabilities, Indiana University*

Debra McLean, *Oregon Technical Assistance Corporation*

Tia Nelis, *President, Self Advocates Becoming Empowered (SABE), the National Self-Advocacy Group*

Tom Nerney, *Co-Director, the National Program Office on Self-Determination*

Clint Perrin, *President, Self-Advocacy Association of New York State*

(Continued on next page)

Tentative Program Agenda

Thursday, July 9, 1998

9:00 - 4:00 PM	Pre-conference workshops A. Self-Advocacy B. Common Vision: Building Knowledge and Leadership from the Inside/Out *sponsored by ACT*
5:00-9:00 PM	Welcome Reception for All Participants and General Registration

Friday, July 10, 1998

7:30-8:30 AM	Registration
8:30-10:00 AM	Opening General Session
10:45-12:15 AM	Concurrent Breakout Sessions
12:15-1:30 PM	Lunch on your Own
1:30-5:00 PM	Concurrent Breakout Sessions
6:00-9:00 PM	Dinner Plenary Session *(Included with registration)*

Saturday, July 11, 1998

8:00-11:15 AM	Concurrent Breakout Sessions
11:15-12:15 AM	Poster Sessions
12:30-1:45 PM	Plenary Luncheon *(Included with registration)*
2:00-4:00 PM	Closing Plenary

The conference is cosponsored by:

TASH

The University of Minnesota, Institute on Community Integration, UAP

Institute on Disability, UAP, University of New Hampshire

The Arc of the United States

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Bonita Scott, *State President, People First of Tennessee*

Kim Sheridan, *Ryerson Communications, Inc., and Communications Director for the National Self-Determination Project*

Don Shumway, *Co-Director, the National Program Office on Self-Determination*

Niki Smith, *Oregon Mental Health and Developmental Disabilities Services Division and member of the Advisory Committee for the National Self-Determination Project*

Michael Smull, *Support Development Associates, Maryland*

Madeline Will, *Vice-President, Community Options, and a member of the Advisory Committee for the National Self-Determination Project*

Self-Determination State Project Directors

Presenters from Advocating Change Together, Inc., *(ACT), a nonprofit disability rights organization from Minnesota*

The conference sessions will focus on strategies to make the four principles of Self-Determination a reality for individuals with disabilities and their families. The principles are:

Freedom – *The ability for individuals with disabilities, along with freely chosen family and friends, to plan a life with necessary supports rather than purchase a program;*

Authority – *The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports;*

Support – *The arranging of resources and personnel (both formal and informal) that will assist an individual with a disability to live a life in the community rich in community associations and contribution; and*

Responsibility – *The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life enhancing for persons with disabilities.*

Look for breakout sessions and roundtable discussions on these topics:

- Medicaid and Changing State Waivers
- Employment Through Individual Budgets
- Self-Advocacy as a Political Force
- Support and Brokerage Agencies
- Fiscal Intermediaries
- HR2020: The Medicaid Community Attendant Services Act (MiCASA)
- Self-Determination as Public Policy
- The New Quality Assurance
- Self-Determination: Using Medicaid to Get From Here to There
- Leaving Institutions
- Individual Budgets: Moving From Institutions to the Community Using Self-Determination
- Communications: Linking Communities Through a Private, National Intranet
- The Waiting List Initiative: Moving Dollars Directly to Families
- Family Roles
- Personal Stories
- Rethinking Money in the Investment of People with Developmental Disabilities
- Managed Care and Self-Determination
- Systems Change
- *and much more!*

General Information

Travel Arrangements

✈ *Airline Information*

Northwest Airlines has been designated as the official carrier for attendees of the Second Annual National Conference on Self-Determination. Service is available to Minneapolis through the Minneapolis St. Paul International Airport. Northwest offers a 5% discount off any published Northwest roundtrip fare purchased with at least 7 days notice and a 10% discount off published fares purchased with over 60 days advance notice. Reservations can be made over the Internet at: www.nwa.com, or by calling 1-800-328-1111. Please refer to Wordfile NY6RM.

Airport Express Shuttle

The shuttle leaves every 15-20 minutes from the Airport Express Shuttle Desk on the Ground Transportation Level. The shuttle cost is $10.00 one way, $16.50 roundtrip. For accessible shuttles please call 612-827-7777 in advance.

Conference Location

Minneapolis Hilton and Towers
1001 Marquette Avenue South
Minneapolis, MN 55403
Telephone: (612) 376-1000
Toll-Free: 1-800-HILTONS

Special Reduced Conference Rate:
Single/Double - $114.00
Additional Person - $20.00
Current state and local taxes are 12%

(ask for the Self-Determination Conference)

Personal Care Services

If you require Personal Attendant Services, please contact: Becklund Home Health Care at 612-544-0315. Please call at least 72 hours in advance to arrange assistance.

♿ Access Accommodations

Sign language interpreters, assistive listening devices, large print and other communication accommodations will be provided upon request. This brochure and all conference materials are available in Braille, as a text file on IBM or Macintosh disk, or in large print on request.

Registration Fees

Registration fees include all conference sessions, morning refreshments, Thursday reception, Friday dinner, and Saturday lunch. All fees must be paid in advance of the conference. Each person registering must complete a separate registration form, indicating if attendance at the meals is planned, and specifying any accessibility requests. **Registration is in advance only and space is limited.**

Full Registration	$184.00
Parent/Self-Advocate Registration	$84.00

(see page 30 to register for the conference)

Scholarships and Stipends

A limited number of scholarships and stipends are available. For more information, please call Denise Marshall 410-828-8274 x 103.

The Second Annual Conference on Self-Determination

REGISTRATION FORM

Please fill out a separate form for each person registering for the conference. Space is limited, so register early! **Registration is advance only. Registrations must be received by July 6, 1998.**

Please register me for the Self-Determination Conference to be held on July 10-11, 1998. General Registration Fee: $184.00 Self-Advocate/Parent Registration Fee: $84.00
I would like a ticket to attend the Friday Dinner Saturday Luncheon (tickets to these events are at no extra charge, but must be requested in advance)

Name: ______________________________

Organization/University/Agency ______________________________

Mailing Address This address is: Home Work

Address: ______________________________

City: ______________________________

State: ______________ Zip/Postal Code ______________ Country ______________

Telephone ______________________ Fax ______________________

E-mail ______________________________

Accessibility Requests ______________________________

Payment Information and Terms

1 Enter Applicable Conference Registration Rate: ____________

Total Enclosed: ____________

Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted for cancellations received before July 6th, 1998. Refunds will not be issued for cancellations after that date. A $15.00 fee for returned checks or unauthorized charges will be assessed.

Check Enclosed Purchase Order/Voucher Number ______________________
Visa Mastercard Discover Card Number ______________________ Exp Date: __________

Signature: ______________________________

Mail Form:
Self-Determination Conference
c/o TASH
29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204

Fax: 410-828-6706
Questions: Phone: 1-800-482-TASH (8274) or 410-828-8274
TDD: 410-828-1306
Website: http://www.tash.org

CORRECTION:

There was an error in The Letter to Chief State School Officers that appeared in the December 1997/January 1998 edition of the TASH *Newsletter*. The following paragraph is the correct final paragraph of that letter. TASH offers its apologies to the co-signers of this letter.

We hope you will proceed in accordance with the Act, and both encourage and enable those schools for which you have responsibility to do so, by adhering to the Act's limitations on the kinds of discipline that may be used and — affirmatively — by aggressively assisting those schools to know and to adopt both the best educational practices and the best classroom management practices.

The University of Washington Graduate Program

trains teachers to serve the needs of pupils with significant disabilities. Emphasis on data-based, systematic instruction referenced to the requirements of natural school and community settings. M.Ed. degree plus initial teacher certification possible. Dr. Felix Billingsley, Area of Special Education, 102 Miller Hall, Box 353600, University of Washington, Seattle, WA 98195, (206) 543-1827, e-mail felixb@u.washington.edu

Special Education Service Agency

Anchorage, Alaska

The Special Education Service Agency currently has two vacancies for an Education Specialist in the following areas. For more information about our organization, contact our website at http://www.sesa.org

Education Specialist - Autism Spectrum Disorders: Minimum Qualifications: Master's degree in education with emphasis on learners with autism spectrum disorders or Master's degree in education with emphasis on the learner with moderate/significant disabilities and extensive course work on autism; minimum of three years recent experience working with learners with autism spectrum disorders.

Experience Needed: (1) developing communication-based support strategies; (2) teaching social interaction and play skills; (3) developing programs to enhance communication skills; (4) current knowledge of assistive technology; (5) knowledge of current research and range of educational practices in the field of autism; (6) qualify for Alaska DOE Special Education Type A Certification. Excellent health; ability to travel extensively and independently in rural/remote Alaska; ability to work collaboratively and independently.

Education Specialist – Orthopedic/Other Health Conditions: Minimum Qualifications: Master's degree in education with emphasis on learners with orthopedic and other health conditions or Master's degree in education with emphasis on the learner with moderate/significant disabilities and extensive course work in orthopedic and other health conditions; minimum of three years recent experience working with learner with orthopedic and other health conditions;

Experience Needed: (1) Developing augmentative communication systems; (2) current teaching knowledge using assistive technology; (3) ability to work collaboratively and independently; (4) qualify for Alaska DOE Special Education Type A Certification. Excellent health, ability to travel extensively and independently in rural/remote Alaska.

Preferred Experience: (1) Working with preschool through high school age ranges; (2) working across student ability levels; (3) experience and/or training with students who are medically fragile; (4) experienced and/or training in traumatic brain injury; (5) training professional and/or para-professional educators; (6) inter-agency networking and collaboration.

For more information about employment or to submit a resume and letter of inquiry, please contact:

Ron Jones, Program Administrator
Special Education Service Agency
2217 E. Tudor Road, Suite 1, Anchorage, AK 99507
907-562-7372 • Fax: 907-562-0545
e-mail: rjones@sesa.org

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

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Mark Partin, *Vice President*
Doug Biklen, *Chair of the Executive Committee*
Joe Wykowski, *Secretary*
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Barbara Buswell
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Michael Kennedy
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Tim Knoster
Deb Kunz
Frank Laski
Liz Obermayer
Linda Rammler

MEMBERSHIP INFORMATION

Referred by:

Name: ____________________

Address: ____________________

City/State/Zip: ____________________

Telephone: (   ) ____________ Fax: (   ) ____________

E-mail: ____________________

Is the above your
work address   home address
other ____________

Please Check Appropriate Categories
(not more than three):

( ) Administrator/Adult Services
( ) Administrator/Education
( ) Administrator/Other
( ) Adult Service Provider/Staff
( ) Behavior Specialist
( ) Case Manager
( ) Early Childhood Services
( ) Educator/Teacher
( ) Gov. Personnel (Federal, State, Local)
( ) Higher Education
( ) Interested Individual/Advocate/Friend
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional Public Policy Advocate
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
( ) Student (College/University)
( ) Supported Employment/Day Personnel
( ) Other

Moving?
Please notify TASH of your new address.

General Membership (individual)	$88.
Agency/business/university/college/library/school (allows 3 conference attendees at the member rate)	$200.
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship)	$45.
Family (group rate)	$136.
Lifetime Member	$1000.

All dues are $15 higher for members outside the U.S. & Canada. Funds must be submitted in U.S. Dollars.

If you would like to charge your membership, please fill in the necessary information.

( ) Mastercard ( ) Visa ( ) Discover

Card Number ____________________

Expiration Date ____________________

Signature ____________________

( ) I would like to arrange to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

How did you learn of TASH: ____________________

What, in particular, inspired you to join: ____________________

What other disability organization do you belong to: ____________________

If you are applying for a student membership, please provide the following information.

Department ____________________

College/University ____________________

Student I.D. Number ____________________

Anticipated year of completion ____________________

( ) Add $15 if you would like to become a member of your local TASH Chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone:410/828-8274 Fax: 410/828-6706

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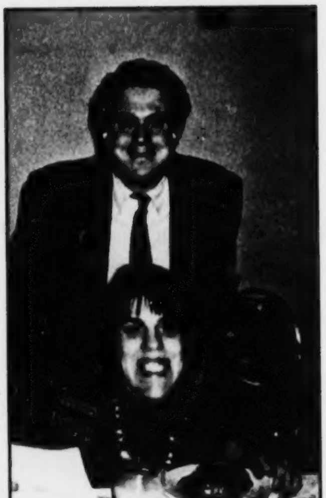
Address Correction Requested

Registration Form for The Second Annual Conference On Self-Determination INSIDE

APRIL 1998

Newsletter



Future Planning for Individuals and Their Families

INSIDE:
Senior Family Caregiver Support Project, States' Waiting List Watch and Providing Support for Families of Adults with Mental Retardation

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

—

Building communities in which no one is segregated and everyone belongs;

—

Forging new alliances that embrace diversity;

—

Advocating for opportunities and rights;

—

Eradicating injustices and inequities;

—

Supporting research and disseminating knowledge and information;

—

Promoting inclusive education;

—

Supporting progressive legislation and litigation; and,

—

Promoting excellence in services.

From the Executive Director
BY NANCY WEISS

TASH INTRODUCES A NEW AWARD

Norris Haring, one of the founders of TASH and an honored lifetime member, and his wife, Dorothy, have established a new TASH award dedicated to the memory of their son, Thomas. The Thomas G. Haring Award will be presented at the annual TASH Conference to the author(s) of a study of particular significance that was published in JASH within the two years prior to the Conference. This $1,000 award will be presented for the first time at the conference this year in Seattle.

Tom received his Bachelor of Science degree in cell and molecular biology from the University of Washington in 1976 and had planned to go to medical school. He decided instead to go directly into work with students with significant disabilities. In 1977, he completed his Master of Science in special education at the University of Kansas. Tom moved to California in 1978 to begin his doctoral study in special education at the Univer-

Continued on page 3

Cover Photos: (Top, l-r) Robert, Bob Jr., Nadean, Roscoe and David. (Bottom) Kenneth and Leslie Moore

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 1998 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions or advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

From The Executive Director

Continued on page 2

Thomas G. Haring

▼ ▼ ▼

> **"The purposes of The Thomas G. Haring Award are to promote research and scholarly activity in the field of significant disabilities, to recognize the achievements of researchers within the field and to continue TASH's positive acknowledgement of contributions to the inclusion of all persons in society."**
>
> — Norrie Haring

▲ ▲ ▲

sity of California, Berkeley, and San Francisco State University, and was awarded a Ph.D. with honors in special education and educational psychology in 1983. He was hired as an assistant professor in the graduate School of Education at the University of California, Santa Barbara, in 1983, where he advanced quickly through the faculty ranks. His promotion to full professor was approved only a few days before his death.

During his distinguished professorial career, he wrote over fifty scholarly articles, many of them with his collaborator and wife, Catherine Breen. Tom's research was significant for its theoretical importance, its methodological rigor, and its practical application. His work focused on the social skills — learning and changing the attitudes of students without disabilities toward their disabled peers. He concentrated on ways to facilitate social and communication skills, particularly as those skills could be used to strengthen enduring friendships among persons with significant disabilities and their non-disabled peers. He studied the dynamics of friendships, how they were formed, how they were maintained, and how already established friendship networks could be applied to include people with disabilities.

In his final year he developed an important model of social integration that recognized the importance that both physical and social context exert on challenging behavior, as well as on pro-social behavior. The high regard for Tom's work led to his being asked to serve on the board of editors of three prestigious journals: the Journal of the Association for Persons with Severe Handicaps, the Journal of Applied Behavior Analysis, and the Journal of Behavioral Education. During his last months of life he was given the Distinguished Professional Award from TASH, an award he prized very highly.

In Norrie Haring's words, "the purposes of The Thomas G. Haring Award are to promote research and scholarly activity in the field of significant disabilities, to recognize the achievements of researchers within the field and to continue TASH's positive acknowledgement of contributions to the inclusion of all persons in society."

To be eligible for the Award the author(s)' manuscript must have been published in the *Journal* during the two years prior to the conference. The senior author must agree to be present at the annual TASH Conference and to present the contents of the paper as a conference session.

Nominations for the award can be made by any current TASH member (see pages 6-7 for the nomination form). Members making nominations will be asked to submit a letter addressing the study's significance, scientific merit, and the importance of its contribution to the disability field. Self-nominations are welcome.

The selection of the manuscript for the award will be made by a committee consisting of Norris Haring, the current Editor of *JASH*, and the current Associate Editors of *JASH*. In addition to nominations received from the membership, Committee members will be invited to nominate published studies for the award.

The Selection Committee can, at its discretion, determine additional criteria for the award that may vary year-to-year. For example, the Selection Committee can announce particular interest in studies on curriculum modification or supports for families of young children. The criteria will be published in the Spring and can be used to encourage the submission of research in content areas of particular interest. This year the award will be granted to a study that significantly contributes to the understanding of educational and community inclusion in general.

TASH extends its sincere thanks to Norrie and Dorothy Haring for their efforts in developing the Thomas G. Haring Memorial Award and for their generous funding of this award.

"CREATING FUTURES TOGETHER"

Seattle, Washington

International TASH Conference
December 2-5, 1998

Headquarter Hotel - Sheraton Seattle Hotel and Towers ❖ For Reservations call 800-325-3535 or 206-621-9000
Workshops and Exhibits - Washington State Convention and Trade Center

(Pre-Conference Workshops & Opening Reception are on December 2, 1998)

Conference Information

Wednesday, December 2, 1998

(Pre-Conference Activities)

- Choose from 15-18 different full day pre-conference workshops on cutting edge issues affecting individuals with disabilities and their families. *(Registration is in addition to full conference)*
- Opening Reception in the TASH Exhibit Hall *(All conference attendees welcome)*

Thursday, December 3, 1998 through Saturday, December 5, 1998

- Choose from over 25 breakout sessions each hour, exhibits, poster sessions, roundtable discussions, creative and performing arts, special interest group meetings, plenary sessions, and much more! Topics on issues affecting the full spectrum of inclusive services for children and adults with disabilities will be presented.

For more information on the conference call 1-800-482-TASH or 410-828-8274 and visit our website at www.tash.org. Look for more information and the registration form in the next Newsletter issue.

The 1998 TASH Conference is in Seattle, the city where TASH was conceived over 20 years ago. No organization existed prior to the formation of TASH that believed that people with significant disabilities were capable and deserving of being fully participating citizens. TASH became the leading organization advocating for the inclusion of people with disabilities. Now, as then, TASH continues to be at the forefront of the fight for justice, equality, and the empowerment for individuals with disabilities and their families.

Join us at the TASH Annual Conference, where the best of hearts and minds in the disability movement gather to provide and share cutting-edge information that inspires advocates, parents, and professionals alike to understand, support, and creatively move forward toward inclusive lives for all.

Inclusion is about all of us, with our different points of view, values, self-interests, and experiences. Come, spend time with over 2400 others who believe in the values you do, and capitalize on the synergy that is TASH. Create inclusive futures - together!

1998

TASH AWARDS

IT'S TIME ONCE AGAIN TO SUBMIT TASH AWARD APPLICATIONS!

Each year at the annual conference, TASH confers a series of awards that recognize individuals, teams, organizations, or media which exemplify the spirit and mission of TASH. Submit your application (found on the following two pages) today!

▶ Who comes to mind when you think of someone who has made a positive difference in the lives of persons with significant disabilities over the past year?

▶ Have you recently seen an outstanding media piece that embodies the values of TASH?

▶ Do you know of a student enrolled in a doctoral program in education or a related field who demonstrates leadership, advocacy, and commitment to efforts of individuals with disabilities?

▶ Is there a team of people working together to improve the quality of life for a person(s) with disabilities?

This is your chance to honor such accomplishments with official recognition. Please take the time to submit an application. Awards will be conferred as part of the TASH Annual Conference to be held in Seattle, December 2-5, 1998. Award applications will be accepted through August 31, 1998. **Please be sure to indicate for which award you are applying on the application, and submit all required documents or information requested for that award.**

1998 POSITIVE APPROACHES AWARD

This award is presented to the person whose contributions have served to advance non-aversive intervention with persons who display challenging behaviors; have demonstrated outstanding efforts leading to the understanding of challenging behavior, and whose actions have advanced the use of non-aversive interventions and progress in the use of positive behavioral supports.

1998 ALICE H. HAYDEN AWARD

This $500.00 cash award will be presented to a doctoral student enrolled in a program in education or a related field and who demonstrates potential for leadership in teaching, scholarship, and service on behalf of people with significant disabilities. The individual needs to have demonstrated a continuing desire in working in partnership with people with disabilities in accordance with TASH values.

1998 MEDIA AWARDS

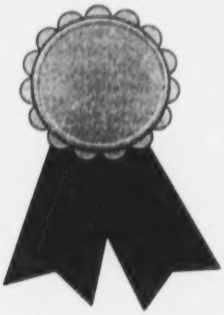
This award is presented to honor presentations in either print or film, which best promote the inclusion of people with significant disabilities in all aspects of community life, and which have reached a national audience. Criteria for selection include: high quality, accuracy of information, meaningfulness of subject matter, potential for consciousness-raising, and promotion of quality of life for persons with disabilities.

1998 COLLABORATION AWARD

TASH will recognize collaborative teams of persons with disabilities, family members, professionals, community members and/or peers, who are engaged in projects and advocacy efforts to ensure the implementation of TASH values in their local community, or in a way that has affected others at a local, state, regional, and/or national level. The work of the recipients of this award should serve as an inspiration for other community efforts, and demonstrate creativity in supporting an individual or individuals to realize the goals of self-empowerment and full community inclusion.

1998 THOMAS G. HARING AWARD FOR RESEARCH

This is the inaugural year for the Haring Award. The award is presented to promote research and scholarly activity in the field of significant disabilities. The award will be presented to the author(s) of a study of particular significance that was published in JASH within the two years prior to the annual conference. The study will have demonstrated scientific merit, and have made an important contribution to the disability field.



1998 TASH AWARD APPLICATION

- Applications due August 31, 1998-

How to Apply:

(1) Complete this application form - front and back- as fully as possible.

(2) Attach a brief narrative discussing why the nomination is being made. Please see the other side of this form for a list of supporting information and materials that must be submitted for the particular award you choose below.

3) Please indicate for which award you are applying. **Check only one award.**

- ☐ Alice H. Hayden Award
- ☐ Collaboration Award
- ☐ Media Award
- ☐ Positive Approaches Award
- ☐ The Thomas G. Haring Award for Research

(4) To be considered, the original completed application and supporting materials must be received in the TASH central office no later than August 31, 1998. Send to:

Awards Committee
TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204

Person or Team Being Nominated:

Name of the Individual: ____________________

Street Address: ____________________

City: ____________________

State/Province: __________ **Country:** __________

Zip/Postal Code: ____________________

Daytime Telephone: (___) ____________________

Evening Telephone: (___) ____________________

Is this individual(s) a member of TASH?
☐ **Yes** ☐ **No**

Name of team members (more room on reverse side)
____

Street Address: ____________________

City: ____________________

State/Province: __________ **Country:** __________

Zip/Postal Code: ____________________

Daytime Telephone: (___) ____________________

Evening Telephone: (___) ____________________

Is this individual(s) a member of TASH?
☐ **Yes** ☐ **No**

Person Making the Nomination:

Name: ____________________

Relationship to the team/person: ____________________

Street Address: ____________________ **City:** __________

State/Province: __________ **Country** __________ **Zip/Postal Code:** __________

Daytime Telephone: (___) ____________________ **Evening Telephone:** __________

FAX:(___) ____________________ **E-mail:** ____________________

Please provide as much information as possible about the persons who are part of this team. Please use additional paper if necessary.

Name of Team Member: ______

Organization (if applicable): ______

Street Address: ______

City: ______

State/Province: ______ **Country:** ______

Zip/Postal Code: ______

Daytime Telephone: (___) ______

Evening Telephone: (___) ______

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

Name of Team Member: ______

Organization (if applicable): ______

Street Address: ______

City: ______

State/Province: ______ **Country:** ______

Zip/Postal Code: ______

Daytime Telephone: (___) ______

Evening Telephone: (___) ______

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

Name of Team Member: ______

Organization (if applicable): ______

Street Address: ______

City: ______

State/Province: ______ **Country:** ______

Zip/Postal Code: ______

Daytime Telephone: (___) ______

Evening Telephone: (___) ______

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

MEDIA CONTACTS

Please provide on a separate sheet of paper, the names and addresses of local radio, television, or newspaper outlets that would be interested in covering the presentation of the award.

AWARD APPLICATION REQUIREMENTS

Collaboration Award:

1. Attach a narrative which describes: a) the goal of the team; b) the interaction of the team members; c) the roles of the individual himself/herself, the family, peers of the individual, and/or people who provide paid support; d) the outcome of the team's efforts; and e) a brief narrative about the individual or individuals who benefited from the collaboration.
2. Attach at least three (3) letters which support the nomination. These letters should present specific anecdotal information or data which conveys an accurate picture of how this collaborative effort met the criteria for the award.

Positive Approaches Award:

1. Attach a description of the nominee's background in the area of severe disabilities. Please include a resume/curriculum vitae if appropriate.
2. Attach evidence of contributions related to positive behavioral support.
3. Attach three (3) separate one page letters in support of the nomination.

Alice H. Hayden Award:

1. Attach a curriculum vitae outlining your history of: a) higher education (including major, minor, degree, date of completion); b) employment (including dates, duties, name of supervisor); c) research and publications.
2. Also attach 500-1000 word essay which describes: a) your current work on behalf of individuals with severe disabilities; b) your educational and professional objectives.
3. Attach at least three (3) letters which support the nomination. These letters should be from professors who are familiar with your qualifications. The letters should present specific data or anecdotal information which convey an accurate picture of your current achievements and potential for significant contributions to the field.

Media Award:

1. Please provide a brief description of the project, including the medium used (radio, television, newspaper, magazine):
2. If the nomination is in the film category, please indicate the length of the video in minutes.
3. Attach two copies of the nominee's work, or of the specific project being nominated. If the nomination is in the print category, the submission must be neat and legible. If the nomination is in the film category, two video copies (VHS 1/2") must accompany the nomination. The submitted work must be sufficient to demonstrate that the work meets or exceeds the criteria for the award.

Thomas G. Haring Award for Research:

1. To be eligible for the award, the authors' manuscript must have been published in JASH within the two year period prior to the conference. The senior author must agree to be present at the upcoming conference, and to present the contents of the paper as a conference session.
2. To make a nomination, submit a letter which references the article, and addresses the study's significance, scientific merit, and the importance of its contribution to the disability field.

Permission to show video submittals:

If the nomination is in the film category, please complete and sign the following to hereby grant permission to TASH to show:

(Title) ______,

as produced by ______,

for, but not restricted to, promotion of the TASH Media Awards and the 1998 Annual Conference. Similarly, as it applies to the promotion of the TASH Awards and the 1998 TASH Conference, the producers waive any monetary compensation .

Signature: ______

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The Senior Family CAREGIVER SUPPORT PROJECT

BY NANCY MELTZER AND SALLY SEHMSDORF

Across the nation, thousands of older families are caring for their loved ones with developmental disabilities at home. While baby boomers age, benefits are cut, and waiting lists grow, the number of such families increases every year. Yet, until recently little attention has been paid to older caregivers. Most family-support policies, programs, and legislation have served families of children and adolescents or younger adults, and make no provision for the caregivers' retirement years, incapacitation, and eventual death.

In the state of Washington, change is under way. Last year, the state family support program provided money for The Arc-King County's Statewide Senior Family Initiative, which surveyed the current situations and long-term plans of nearly 100 senior families. This year, the funds support Pathways to Future Planning, which develops and distributes packets on long-term planning. For the past two years, the Division of Developmental Disabilities has enabled the Senior Family Caregiver Support Project at The Arc-King County to assist older King County families. Project components include an advisory committee (with at least 50% senior families); training, advocacy and referral services; long-term planning assistance for a pilot group of five senior families; and technical assistance and training for community and government.

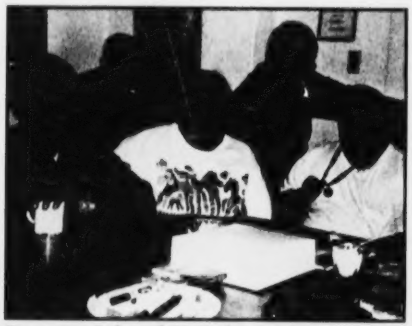
To better understand the issues, concerns, and obstacles facing older caregivers, Senior Family Project Coordinator Nancy Meltzer and Seattle-based TASH project staff member Sally Sehmsdorf visited two families to gain insight into how these families deal with the issues of aging caregivers. Both sets of parents rejected the standard advice to institutionalize their child and drew on a blend of private and public resources, particularly the precious resource of an extended family. Both families realize now, as they age, they need to address the long-term support needs of their adult children. Yet, there are still many unknowns in the future of David, now in his late thirties, and fifty-four year old Marie.

Most family-support policies, programs, and legislation have served families of children and adolescents or younger adults, and make no provision for the caregivers' retirement years, incapacitation, and eventual death.

THE STORY OF DAVID'S FAMILY

Robert and Nadean moved to Seattle with their baby daughter, Mary, in the late fifties. The young African-American couple wanted to escape the racism of the South, and chose Seattle as a better place to raise their children. Robert's brother, Roscoe, had already adopted Seattle as his home and encouraged them to join him. Soon after their move, Bob Jr. was born, followed in 1959 by David.

Robert found a teaching job in the Seattle school system, and before David was born, he and Nadean moved into the home where they and David still live. We met with Robert, Nadean, Bob Jr., Roscoe, and David to hear their story. Robert and Nadean's daughter, Mary, was unable to leave work to join us on the day we visited, but she did manage to call and say hello.



Front row: Robert (left) Nadean and David. Back row: Bob Jr. and Uncle Roscoe

From birth, David was not only nurtured by his parents but surrounded by the love and support of the rest of his family. Bob Jr. fondly recalls early times with his younger brother, and describes his fears for him, based on the doctor's incorrect prediction that David would die young. Uncle Roscoe's home has always been open to David. David took his first steps for Robert's parents, who lived for several years in a small house behind their son's home. During an extended visit, Nadean's mother and David spent hours on the front porch, talking together in their own special language.

As the primary caregiver for many years, Nadean recognizes that her family made it possible to do more with her life than just be David's mom. "If it weren't for the support of my immediate family, I wouldn't have been able to do anything."

A strong neighborhood network further bolstered the family. People looked out for one another, played together. There were picnics, barbecues, and tree houses. Bob Jr. recalls that the kids on the block were close-knit and that David was part of the group.

Once during David's middle school years, Bob and Nadean decided to try placing David in an institution, at that time the only out-of-home choice. But

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The Senior Family Caregiver Support Project

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their decision was quickly reversed. Robert recalls that after dropping David off, the family drove to Mt. Ramier, where Bob Jr. and Mary were sorry David wasn't there to enjoy the deer. Roscoe cannot forget the beds "shaped like cages." Within a month, David was back with his family.

Today, Nadean, Robert, and David live a good life in the family home. Bob Jr., Mary, Roscoe and most of Roscoe's children live close by. To his father, David is a loved companion. They go camping together. Sometimes Robert wonders if he is "selfish" because he does not want his son to leave home.

David makes important contributions to the household, washing and vacuuming floors, storing groceries, folding laundry, and collecting mail. He learned many of these skills at a local community-college food service program. There, David had his first real job, and he relished the experience. But the program was downsized and David was let go.

The loss of the job has been difficult for David and his family. When they drive by the college, David points to "his school." In retrospect, Robert wonders if the agency adequately supported David. Nadean regrets not aggressively pursuing the issue, as she would have done in the past. Yet, the couple agree that David's termination came during a very difficult time for them, just as they began to face many of the problems common to aging families. The death of Nadean's brother, her mother's declining health, and health problems of her own all claimed her attention and diverted it from David.

Since then, the family has begun to think about what David will need when they are no longer here. Robert notes, "You start to think down the line and there are a lot of 'what ifs' developing in your mind." They have explored resources and visited group homes in the community, finding some excellent and some very poor.

After much consideration, Robert has decided it would be best for David to stay in the family home, the only home he has ever known. "He would have his house and his room, it would be personal." When Robert and Nadean can no longer offer support and assistance to David, Robert would like a family member or some other nurturing person to move in. Other people would be hired to assist David, as needed. Bob Jr. and Mary would become co-guardians. Roscoe would manage David's trust fund, with a niece as stand-by.

Robert concludes, "I am looking at how we can keep a family together. Family means a lot to me."

David (left) and his brother, Bob Jr.

Other family members express different views. Bob Jr. says, "I have already decided [David] is going to stay with me even if they (Robert and Nadean) don't want him to." He adds, "After a while, they won't be able to say no, anyway." Roscoe appreciates being included in the planning process, seeing it as a way to clarify his role as "extended family."

Robert proposes yet another solution. Why not invest in a family business that would employ David? This would provide the "permanency" and "trust" which are hard to come by in the community.

Reflecting on forty years of caregiving, Nadean and Robert encourage other families to explore community resources and to decide what is best for their family. They also recognize as families' age, many need extra assistance. "Without it, they are doomed." Concerning the future, Robert advises younger families "to look down the road a bit because it is going to face them." Nadean adds that it is hard for younger families to have that vision "because they have so much to deal with in the beginning."

What is next for David's family? While they have built a foundation of their vision of David's future, much planning remains. A person-centered planning process could offer much to forward their dream. In the coming year, Sally Sehmsdorf and Nancy Meltzer hope to meet regularly with the family and to offer them this kind of planning assistance. The following are suggested areas to explore in subsequent meetings.

1. **What needs to happen in David's family for them to move ahead in planning for his future?**

- Build a profile of David, what is important to him, what he enjoys doing, new things he would like to try.
- Create a vision of David's future life in the family home.
- Expand the family and informal network to participate in the planning process.
- Explore planning a family owned business that would employ David.

2. **What kind of assistance and resources would help the family move forward in the planning process?**

- technical assistance to assist them in the planning process (e.g. keeping minutes, facilitation of meetings, enlisting the support of others);
- invite other important people in David's life to help plan for his future life in the family home;
- expertise in networking in the informal community (e.g. explore the potential of business and work opportunities);
- access to legal and financial planning to support their vision of the future, and
- connections to other families with similar interests (e.g. long-term supports in the family home, developing family business opportunities).

3. **What is the role of government in supporting David and his family and other families with similar needs?**

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The Senior Family Caregiver Support Project

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- Sponsor and fund trainings, advocacy, and planning services for families.
- Support innovative approaches to using public funds to encourage family-driven projects.
- Create support systems that sustain multi-generational family involvement.

THE STORY OF MARIE'S FAMILY

Tonight is Helen Marie's first night in her new home. Her older sister, Suzy, drove her there this morning. In the car, Marie sang enthusiastically "I'm moving, I'm moving." After more than fifty years with her parents, she has entered an adult family home. Her mother, Lorene, her sister, Suzy, and her nephew, Dan, and his wife, Angie, have gathered at Lorene's home to tell us Marie's story and the events that led up to this momentous move. Suzy's older children, Vicky and Ed, are unable to attend, but their messages of love and support are very much with the family this evening.

Marie and her dog, Zoe, in their new home

Marie was born in Wisconsin in 1944, near the end of World War II. Lorene tells us that physicians were experimenting with a new birthing method, which involved delaying the delivery as long as possible. Marie was born cold to the touch and, as her family later came to realize, with a disability.

Medical professionals had little to offer. They advised placing Marie in an institution, telling Lorene "You'll have other children." Victor, Marie's father, and Lorene did not take that advice. They moved to Indiana, where Marie entered kindergarten. School officials invited a famous physician from London and an expert in disability, to examine Marie. He said, "Marie will never learn to read or write." Little did the expert know that Lorene had already taught Marie to read. Marie later successfully passed other typical milestones, including learning to ride a bike.

In 1951, the family moved to Washington where there were reported to be excellent programs for people with disabilities. Suzy believes that Marie did not learn much in these programs. She went to three "special" schools until she was thirteen. At that age, a child deemed "vocationally able" was referred for additional training. Marie was evaluated as neither "vocationally able" nor "educable," and the recommendation was "no further schooling." In June of 1957, Marie left school for good. Her parents were told, "Just keep her home."

Still, Marie at thirteen was a typical teenager. She adored Eddie Fisher, was very good at recognizing talent on the Arthur Godfrey show, and loved classical music and dancing. She was neat and organized and always kept herself busy. As she grew older, she had the opportunity to take road trips up and down the coast with her parents. Marie and her dad shared a love for fine cars, and Marie could recognize and name all the different makes.

As children, Marie and Suzy had always been close. During the mid '60s, Suzy married and began a family of her own, and Marie, then in her twenties, was included in Suzy's new life. Marie saw a house being built, children being reared, lots of pets, especially dogs. She shared holidays with extended family, meeting and enjoying new people. She grew close to all three of Suzy's children, Vicky, Ed, and Dan.

In the 1980s, Victor, Lorene, and Marie moved to Hawaii. Marie's twelve-year-old nephew, Dan, came to visit. Dan and Marie spent a lot of time together and Marie, who had always had an amazing memory, shared family history with him. Today, Dan believes those visits cemented their relationship.

Lorene, Dan, Suzy and Angie

The family eventually returned to Seattle. Victor and Lorene were dissatisfied with Hawaii's services for people with disabilities. Victor was particularly offended by the congregation of people with disabilities, and saddened by the sight of people paraded throughout the community in large groups, holding hands. Also, people from the system told him and Lorene, "You are getting older and you should be putting her someplace." Victor didn't want to put Marie in a "place." But he realized that he and his wife were growing older, and that Lorene could not care for Marie alone.

Marie's family, no less than David's, had to deal with bad times as well as good. Marie's world was limited. She had no companions her own age, only her Mom and Dad and their friends. Suzy felt that Marie was frustrated at the limitations of her lifestyle and the dependence imposed by aging parents. Over the last ten years, Marie was increasingly angry and self-abusive. Suzy acknowledged to her parents that Marie could not live with her. That was a difficult message for Victor. Victor wanted Marie to remain in the family home.

Victor died in 1997. Marie understood that he was gravely ill. She remarked during his final days that "Victor" was gone, "all" gone, and then named family, friends, and animals that had died. After her dad died, Marie grieved. Her final good-bye to the father she loved came one morning as she looked down at his car and said, "Good bye little Fleetwood, it's been nice."

In the time since Victor died, Lorene, Suzy, Dan, and Angie have struggled with the challenge of Marie's future. After speaking with local agencies, they realized the only available option was an

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Adult Family Home. They've found one that looks promising.

What do they hope for Marie's future? They hope that at fifty-four, Marie will finally become her own person. They hope she will meet new people, have more choices, and gain more control over her life. They hope she will have more activities to stimulate her, relearn to read and write, and have the chance to travel. They envision visiting her weekly in her new home. Suzy is hopeful that the adult family home will offer her sister a good life. They have dogs, have offered to take Marie on trips, and greeted her this morning with a big sign that read "Welcome Home Marie." If all goes well, Marie will enjoy her new home, and the home will live up to its promise to provide more than just its contractual obligations of board and care.

What's next for Marie and her family? The death of a parent compelled Marie's family to make an initial long-term care decision without the benefit of planning. They still have hopes and dreams for Marie's future. There remains ample opportunity to enhance the current and future quality of Marie's life.

Using a person-centered planning process, Sally and Nancy hope to continue to meet and work with Marie and her family. The following are suggested areas to explore in subsequent meetings.

1. **What needs to happen in Marie's family for them to move ahead in planning for her future?**

- Provide time and support for Marie to settle into her new home.
- Get to know Marie and learn about what she would like to experience in her new life (including finding ways to support the Marie who enjoyed reading, riding a bike, following the different automobile models, traveling).
- Develop a lifestyle plan to address Marie's interests and goals in her new life in the community.
- Sustain the multi-generational involvement of the family in planning.
- Include the Adult Family Home in the planning process.

"What will happen to my family member when I am no longer available?"

2. **What kind of assistance and resources would help the family move forward in the planning process?**

- technical assistance to assist them in the planning process (e.g. keeping minutes, facilitation of meetings, enlisting the assistance of others);
- access to experts to vigilantly ensure quality of life for Marie in the Adult Family Home, including enhancing opportunities for community involvement and personal self-development;
- networking with other families whose loved ones reside in Adult Family Homes;
- opportunities to explore alternative living arrangements in the community;
- assistance in exploring work and leisure time pursuits in the community. (The family needs to learn about the possibilities and Marie needs opportunities to personally experience the options.); and
- consultation on ways private funds can augment public resources (e.g. trusts can purchase supports unavailable in the residential setting).

3. **What is the role of government in supporting Marie and her family and other families with similar needs?**

- Fund and sponsor training, advocacy, and planning services to families (e.g. benefits, financial, legal, and residential).
- Build in family connections and involvement subsequent to out-of-home moves.
- Offer intensive in-home supports to at-risk families (e.g. those experiencing loss and grieving) to prevent precipitous placement decisions.
- Support the development of positive lifestyles in Adult Family Homes through adequate funding, training, and technical assistance.
- Develop policies and procedures that allow private (e.g. trust) resources to blend with public (e.g. Medicaid) funds to provide a comprehensive package of supports and lifestyle opportunities.

We have learned much from our community's older families. The majority share one overwhelming question: "What will happen to my family member when I am no longer available?" But few have acted on this concern. Nor have most caregiving families addressed their own long-term needs, so closely tied to those of their children. In order to effectively plan for the "day after," families must face their deepest fear: that of their own mortality. They must prepare themselves to look beyond the safe confines of their own households, reach out to others for support, and trust in the unknown to carry out their wishes. It is a formidable task that awaits all families in the developmental disability community.

Project coordinator Nancy Meltzer would like to hear from others who share an interest in outreach to older families. She can be reached at: The Arc-King County, 10550 Lake City Way NE, Suite A, Seattle, WA 98125; (206) 364-6544; fax (206) 364-8140; e-mail Nanmeltzer@aol.com.

In order to effectively plan for the "day after," families must... prepare themselves to look beyond the safe confines of their own household, and reach out to others for support.

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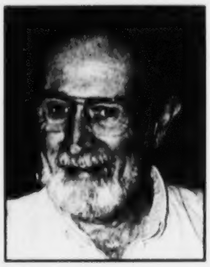
In Memory Of... RICHARD LEPORE



On April 24, 1998, people with disabilities, their families, and those working toward positive change lost a great leader. A diplomat, activist, visionary, politician, and teacher, Richard Lepore worked vigilantly on behalf of people with disabilities for more than 25 years. He believed strongly in the ability of communities to welcome and support all people and questioned the capacity of systems and agencies to provide long-term assistance. Dick deeply touched the lives of hundreds of people, and leaves a legacy that will endure and energize us long into the future.

With characteristic dignity, grace, and courage, Dick waged a 10 year battle with leukemia. Several months prior to his death, he wrote the following obituary. It does not begin to adequately describe his contributions, and achievements.

Richard Lepore was a resident of Eliot, Maine, and a long time health administrator for both Maine and New Hampshire. Dick struggled with leukemia while continuing his affiliation with the Institute on Disability at the University of New Hampshire. He was a veteran of the Air Force and was an instrument rated private pilot. Dick earned a Master's degree in Counseling Psychology from the University of Alaska at Anchorage, and became well-known in New England for his leadership in developing systems of support for people with disabilities and their families. Mr. Lepore served as Director of the Elizabeth Levinson Center in Bangor, Maine, and as state director of the developmental disabilities systems in both New Hampshire and Florida. He is perhaps best known for his role in the closing of Laconia State School in New Hampshire, allowing New Hampshire to become the first state in the United States to operate a system of services without being dependent on a large, congregate, state facility. He is also well-known for establishing a state-wide system of independent support coordination for people with developmental disabilities in Florida.

In addition to his wife, Paula, Dick is survived by two daughters, a son, and three grandchildren. Also surviving Mr. Lepore are his mother, a half brother, and a half sister.

Accomplishments included employment as deputy director for residential services in Sacramento, California, and assistant professor in the Human Services Department, in Bangor, Maine. Dick also held positions in the field of developmental services in Waltham and Taunton, Massachusetts; and served as a teacher, presenter, consultant, and policy advisor in the United States, Canada, and England.

In September 1996, Dick received the Chairperson's Award for Distinguished Service by the President's Committee on Mental Retardation.

Donations may be made to the "Richard Lepore Memorial Fund," to further the work of inclusion of people with disabilities into community life. Donations may be sent in care of: Kim Frederic-Klein, 13 Maplewood Drive, Barrington, New Hampshire, 03825.

TASH gratefully acknowledges the assistance of Jay Klein in contributing biographical information and personal insights for this article.

VANDERBILT UNIVERSITY
PEABODY COLLEGE OF EDUCATION AND HUMAN DEVELOPMENT

Assistant Professor — Visual Disabilities

The Department of Special Education, Peabody College of Vanderbilt University, is seeking an assistant professor with expertise in the area of Visual Disabilities for a three-year appointment beginning August 1998. This is a non-tenure track position with the possibility of conversion to tenure track after the initial three-year term. Teaching responsibilities include four courses per year, primarily at the masters level. Student advisement and practicum supervision, as well as participation in the development of the program in visual disabilities, are expected.

Qualifications include doctorate in special education or a related field; college teaching experience in special education and visual disabilities; excellent instructional skills, including enthusiasm for teaching, supervising, and advising students; teaching and service delivery experience in visual disabilities; experience and interest in program development and teacher education; and evidence of scholarly productivity and research. Preference will be given to candidates with experience in securing external funds for research, training, and program development and to candidates with expertise in orientation and mobility, technology, and/or multiple disabilities.

Applications for this position will be reviewed beginning May 1, 1998. Please send a letter of application, vita, reprints of two articles, and the names of three references to Dr. Anne Corn, Chair, Vision Search Committee; Department of Special Education; Box 328 GPC; Vanderbilt University, Nashville, TN 37203.

Inquiries may be directed to Dr. Corn at 615-322-2249, or e-mail anne.corn@vanderbilt.edu Vanderbilt is an equal opportunity, affirmative action employer with a strong institutional commitment to diversity in all areas. The university actively seeks applications from women, minorities, and individuals with disabilities.

Future Planning
FOR YOUR CHILD
Takes More Than a Will

Because of medical advances, more children with disabilities are living longer. Many adults with Down syndrome, for example, are living long enough to retire and collect Social Security. The difficult part of this wonderful longevity is that in many cases, children outlive their caretaker parents. For any child, the death of a parent is a tragic event; for a child with a disability, the death of a parent-caregiver can be especially traumatic.

If you are the parent of a child with a disability, have you considered what arrangements you've made for your child in the event that both you and your spouse die before your child? Many parents of children with disabilities are making detailed plans to cover this eventuality. For children with disabilities, a plan of this kind will ensure an emotionally and financially secure future — and a smoother transition to a life without their parents.

Where to begin

This kind of comprehensive planning should begin when your child is first born and should be reviewed and changed at different stages in the child's life. "Future planning is an ongoing, dynamic process," writes Rick Berkobian in his book, *A Family Handbook on Future Planning*. Berkobian, assistant director of research and project planning for the Arc in Houston, Texas, established the Arc's future planning program. Future planning not only helps your child, but allows you to feel more secure about your child's future after you are gone.

Start with the present

A thorough future planning program encompasses all aspects of your child's life. First, you should look at the child's existing assets, abilities, and needs — identifying and assessing the child's:

- Ability to be physically and emotionally independent
- Available financial support and emotional supports — both inside and outside the family
- Social life
- Use of community supports and services
- Current education needs and any costs involved
- Employment status and the existing supports associated with it
- Transportation needs and how those needs are met
- Eligibility for government or other financial programs
- Level of self-care and other skills

If possible, promote self-confidence and teach your child decision-making and other self care skills early in life. This will help to ensure your child's success in education, employment and other areas of their lives — with or without you.

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If you are the parent of a child with a disability, have you considered what arrangements you've made for your child in the event that both you and your spouse die before your child?

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Move to the future

Next, parents should assess what the child will need in a future that does not include them. Whenever possible, include the child in the planning process and ask for his or her input.

Besides guardianship and financial considerations, plans for a minor child would include arrangements for their elementary, high school, and college education or other post high school training. Address questions that cover every eventuality that the child will be faced with after your death. These include:

- What is needed to prepare the child emotionally for the eventuality of the parents' death?
- Who will the child depend upon for emotional and physical support after the parents are gone?
- What self-care, decision-making and life skills does the child need to learn to live successfully?

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Future planning not only helps your child, but allows you to feel more secure about your child's future after you are gone.

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Parents should assess what the child will need in a future that does not include them. Whenever possible, include the child in the planning process and ask for his or her input.

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- What will the child's housing needs be?
- Who will the child live with?
- What can be done to help the child make new circles of friends and helpers as time goes on?
- For young adults, what plans are needed to ensure a successful transition from school to work?
- What additional education or training will the child need?
- What costs will the education and training entail?
- What will the child's transportation needs be?
- How much responsibility can the child assume?
- What financial supports will the child have from life insurance, savings, trusts, and so on?
- What government financial supports will be available for the child?
- What medical care will the child be eligible for?
- What will an adult son or daughter do when he or she retires from the world of work?
- What will the child's social life be like?

A trusted guardian should be designated for a minor child, or an adult who needs one. Discuss with the prospective guardian your desires for your child's future, and ensure that your guardian is willing to carry out these desires and accept full responsibility for guardianship.

Review your future plan with an eye to how much responsibility the child can assume for him or herself. The more independence the child is given, the better it will be for his or her well-being. If money expenditures or housing needs are beyond the potential earning power of the child, then a trust attorney and tax expert should be consulted to see how a part of your current funds can be set aside and used later - without jeopardizing the child's access to benefits from other sources. Through insurance, trusts, and investments, a certified financial planner can ensure that sufficient funds are accumulated to cover all of your child's expenses after your death.

For your son or daughter who is an adult with disabilities, the family needs to plan for a structure that draws on the community for emotional support for the adult. This is becoming more and more necessary as extended and nuclear families in today's society become smaller, with only one or even no siblings for the child to rely upon after his or her parents have died. The more religious, social and recreational activities your child is involved in, the better. With these activities, your child can develop friendships and increase the base for his or her emotional support.

Pulling the pieces together

If you die without preparing a will, this could jeopardize the implementation of your carefully crafted future plan. After the future plan is complete, parents should consult an attorney to draw up a will that incorporates all areas of the future plan.

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Probably the most difficult part of future planning is realizing that the person doing the planning will be out of the picture.

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Planning for the disbursement of assets after your death is something that every family should do. Understanding the implications for Social Security, wages, living arrangements and other questions of future income takes specialized planning. The Arc and others provide helpful written materials to cover these questions. Consulting a financial planner and an attorney are advisable for this part of the planning.

Planning the living arrangements for the child is another significant decision. In addition to providing a place where the child can live safely and comfortably, parents must consider the ramifications of placing property and its upkeep in a trust. And, of course, the most important part of the equation is the emotional well-being of the child, and your assurance that the child has the ability to continue to enjoy life.

Probably the most difficult part of future planning is realizing that the person doing the planning will be out of the picture. If you provide your child with emotional, coping, and decision-making skills, and a circle of community and family supports, then develop plans for your child's financial, housing, and other needs, you will have the assurance that your child will succeed after you are gone.

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For more information about future planning, contact:

- The Arc National Headquarters
  500 E. Border St., S-300
  Arlington, TX 76010
  817-261-6003
  817-277-0553 (TTY)
- Clearinghouse on Aging and Developmental Disabilities, The University of Illinois at Chicago, 1640 W. Roosevelt Rd., Chicago, IL 60608-6904, 800-996-8845, 800-526-9844 (TTY)

The Second Annual National Conference on Self-Determination

Minneapolis Hilton Hotel
July 10-11, 1998

The Second Annual National Conference on Self-Determination , sponsored by The National Program Office on Self-Determination, a project of The Robert Wood Johnson Foundation, will feature two full conference days with in-depth presentations and discussions around the issues critical to making the concept of self-determination a reality. Self-Determination refers to a range of efforts aimed at assisting people with disabilities and their families to choose what supports they receive, determine how they live and work in the community, and control their own funds for supports. Participants will have the opportunity to interact with leaders in the self-determination movement through an extraordinary range of plenary sessions, workshops, discussion forums, luncheon and dinner presentations, poster sessions and informal networking opportunities.

— PROGRAM AGENDA —

Pre-Conference Workshops
July 9, 1998

8:00 AM - 5:00 PM

Common Vision: Building Knowledge and Leadership from the Inside/Out
Sponsored by Advocating Change Together, Inc. (ACT)
(Separate registration required. For information on registering, call ACT at 612-641-0297)

8:00 AM - 9:00 PM

Gathering of State Self-Advocacy Organizations
Sponsored by The Collaborative on Self-Determination
(By Invitation Only) For information call
Leanne Boyce 615-898-0025

5:00 - 9:00 PM

Welcome Reception for All Participants and General Registration

Friday, July 10, 1998

7:30-8:30 AM	Registration
8:30-10:00 AM	Opening General Session
10:45 -12:15 PM	Concurrent Breakout Sessions
12:15-1:30 PM	Lunch on Your Own
1:30 - 5:00 PM	Concurrent Breakout Sessions
6:00 - 9:00 PM	Dinner Plenary Session

(Included with registration) Includes a performance by Interact Center for the Visual and Performing Arts entitled "My Choice, But Your Decision."

Saturday, July 11,1998

8:00 - 11:15 AM	Concurrent Breakout Sessions
11:15-12:15 PM	Poster Sessions
12:30-1:45 PM	Plenary Luncheon *(Included with registration)*
2:00 - 4:00 PM	Closing Plenary

For a complete brochure, please call the TASH Central Office at 410-828-8274 x103.

Please note: Dr. C. Everett Koop, Former Surgeon General of the United States, will not be able to attend the conference as reported in the April issue of the TASH Newsletter

ParaEducators LifeLines in the Classroom

1998 Trainer-of-Trainer Sessions

Build in-district resources to ensure on-going paraeducator training by attending this 3-day workshop to become a ©LifeLines trainer.

Offered by
LRCONSULTING:
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THE LIST GROWS ON AND ON

TASH gratefully acknowledges the assistance of Sharon Davis, Ph.D., Director, Department of Research and Program Services, Alan Abeson, Ed.D., Executive Director and June C. Lloyd, Intern, of The Arc of the United States, in allowing us to reprint excerpts of its November 1997 report, "A Status Report to the Nation on People with Mental Retardation Waiting for Community Services."

The Waiting List Problem

Since the early 1970s, families have been encouraged to keep children with disabilities at home. Many of these children, especially younger ones, can benefit from early intervention and other services, and their families can be greatly helped by family support services, such as respite care, counseling and cash subsidies. This is where many families start to learn about waiting lists, as the service(s) they need or want may not be available to them.

As these children become adults, many still live with their families. Older families especially, who have kept an adult family member at home over the years, are astounded by the waiting list situation. Sometimes, parents in their 80s learn they must wait 10 or 12 years for services! Because of long waiting lists for existing residential services, these senior parents and other caregivers have difficulty developing thoughtful future plans. They are under a tremendous amount of stress and worry. Some parents believe that the only way off the list for their adult son or daughter is for the parents to suffer serious illness or die. This was true for a New Jersey father whose adult family member finally obtained a home in the community after he suffered a massive stroke.

This suffering is not limited only to families, but also to thousands of individuals who are also waiting. Many of them are young people leaving school only to encounter waiting lists for employment and other day services. They are often deprived of the opportunity to experience full life in the community. As these people age, their families cannot help them make the transition to a new living situation and ease the way to such change before the parents die. This means that when the crisis hits, the person with mental retardation loses a parent and moves out of the family home at the same time — a traumatic situation all around.

The Numbers Are Astounding

Many thousands of individuals and families in the United States depend on community supports and services to assist them in meeting their needs or those of their family member. Tragically, however, in most states when these individuals and families seek services and supports, they come face to face with lengthy and sometimes unending waiting lists.

In 1987, The Arc of the United States conducted the first ever study of waiting lists for community services (Davis, 1987). That study found 63,634 individuals with mental retardation waiting for residential services and 76,039 waiting for day/vocational services, for a total of 139,673 services needed. Some individuals were waiting for more than one service which, on the surface, gave the appearance that the total number of people was somewhat fewer than the total number of services needed. However, because of the data gathering mechanisms used by states (see Study Methodology on page 18), it must be acknowledged that the number of people waiting for community services probably does not accurately reflect the true degree of need.

Ten years later, The Arc conducted a follow-up examination of the status of waiting lists for community services reported by states. The study found 52,072 waiting for residential services; 64,962 waiting for day/vocational services; and 35,862 waiting for either or both, for a total of 152,896 services needed. In addition, data was collected on a variety of services not strictly residential or day/vocational and found 65,290 people waiting. The total services needed by individuals in communities was 218,186 in 1997.

Additionally, there were 5,376 people in state institutions waiting for community placement in 16 states that reported such data. That brought the grand total of services needed to 223,562 in the 48 states reporting waiting list information. Finally, if all 53,661 people living in state institutions as of last November were added to the waiting list, the waiting list for community services would grow to 271,847.

To describe the waiting list situation as a crisis for America is not an exaggeration. The findings of these studies makes clear that in the 10 years since The Arc first collected this information, the situation has grown worse.

The National Waiting List

The number of community services requested by families across the country in the 48 states that provided data was 223,562. While four states reported no waiting lists, other states with no data collected acknowledge they know people need services. They simply have not created the capacity to collect the data on a statewide basis. The states falling into this category are Iowa, Ohio and West Virginia. Illinois collects data on waiting lists for its family support program only. Wyoming reports no adults waiting for residential or day/vocational programs, but 12 children are reported as waiting for services.

Caution is urged in interpreting the numbers of services for which people are waiting in each state. While some states are quite con-

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fident that their data collection process is at least capturing those with the most needs, other are unsure.

Study Methodology and Results

How the Study Was Conducted

State chapters of The Arc were contacted by mail and requested to assist in collecting information on waiting lists from the appropriate state agency or to provide a contact person who would have the waiting list information. Where additional information was needed or where there was no state chapter of The Arc, the state Developmental Disabilities Council or the state mental retardation/developmental disabilities agency was contacted. Written reports on the waiting list were obtained if available.

The nature of the data varied from state to state. Some states maintained detailed information on types of services requested; others did not. No attempt was made to collect data on waiting lists for transportation services. In reality, however, a lack of transportation deprives many people with disabilities from taking advantage of services which do exist.

The numbers collected for this report represent numbers of people waiting for a particular service category. Some people are waiting for more than one service in all but 15 states. Therefore, the total waiting list represents number of individual services needed. The number of individuals waiting for services will be somewhat fewer. In a 1991 survey of people on waiting lists, it was estimated that 19.5 percent of the reported number of people waiting for services could be attributed to duplicate counting (Hayden, 1992).

The data in this report represent the most recent numbers collected by each state and reported to The Arc during the months July-October 1997. In most cases, the numbers represent people on the waiting list in 1997. A few states reported 1996 data.

Information regarding waiting lists was obtained from all states and the District of Columbia. Four states reported no waiting lists (California, Kansas, Nevada, and Rhode Island). Three states did not collect statewide data (Iowa, Ohio, and West Virginia). Several other states collected limited waiting list data (i.e. Medicaid waiver only in Idaho; family support only in Illinois). Several states did not break out the list by type of service for which people were waiting.

Data was collected by states in a variety of ways, and as indicated, few states believe that they accurately identify all of the people with service needs. Most states recognize that many families may not choose to put their family member's name on a waiting list, if they believe it is unlikely to result in a service.

Wisconsin, for example, noted that the 2,215 people who are on waiting lists for a place to live represent a fraction of the 7,600+ adults with developmental disabilities who are currently living with family members (and not receiving any paid residential supports). On the other hand, there may be individuals on the waiting list who would refuse services if offered, particularly

TABLE 1:
Community Service Needs: Waiting List

The following numbers represent services needed and should not be considered the total number of individuals requesting services and supports. Only 15 states indicated that the numbers reported were unduplicated numbers of individuals waiting.

State	Total Number of Services Requested
Alabama	6,653
Alaska	1,275
Arizona	662
Arkansas	1,966
California	No waiting list reported
Colorado	1,182
Connecticut	2,111
District of Columbia	58
Delaware	429
Florida	6,516
Georgia	3,046
Hawaii	1,395
Idaho	192
Illinois	3,725
Indiana	2,067
Iowa	Data not collected
Kansas	No waiting list reported
Kentucky	1,778
Louisiana	13,958
Maine	1,759
Maryland	7,494
Massachusetts	3,187
Michigan	2,946
Minnesota	2,378
Mississippi	775
Missouri	1,774
Montana	871
Nebraska	2,062
Nevada	No waiting list reported
New Hampshire	193
New Jersey	5,496
New Mexico	1,790
New York	50,225
North Carolina	12,654
North Dakota	137
Ohio	Data not collected
Oklahoma	2,035
Oregon	7,313
Pennsylvania	28,000
Rhode Island	No waiting list reported
South Carolina	2,293
South Dakota	27
Tennessee	3,567
Texas	11,084
Utah	3,087
Vermont	249
Virginia	4,871
Washington	7,149
West Virginia	Data not collected
Wisconsin	7,745
Wyoming	12
TOTAL	218,186

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residential, as they are not ready to move from the family home at the present time.

A survey of waiting list families in Massachusetts revealed 33 percent estimated they would need residential services in 2-5 years and 18 percent "in the distant future."

In some cases, individuals whose names are on a waiting list for a particular service may already be receiving some service. However, they desire additional services or a different type of service. A person living in a group home could be on a waiting list for a supported apartment, for example. Or, someone who was receiving supported employment services could be on a waiting list for counseling, if counseling services were scarce. While Pennsylvania has a waiting list of 28,000, it is believed that only 2,000 are not receiving any services.

Action is Needed to Solve the Waiting List Problem

Waiting lists are a critical public policy issue in almost every state. However, advocates in many states have failed to communicate successfully the immediacy of family and consumer needs to legislators and others. A large number of families and individuals with disabilities on the waiting list need services now, not some time in the future. A survey of families on the waiting list for residential services in Massachusetts found 40 percent needing services immediately or within a year or two. The caregivers were in poorer health; their sons and daughters had significantly more behavior problems; and fewer had estate plans or designated guardians in their wills than the 60 percent who needed services later.

Many states have a high percentage of people on the waiting list classified as in a crisis or high need situation. In Utah, one such family has been on the waiting list for 18 years and classified as "critically in need of services" for 10 years. Once again, the only sure way for an individual to receive services in many states is for the caretaker to die.

Another issue that goes largely unrecognized is the number of families unknown to the service system. Pennsylvania recently reviewed applications for nursing home placement by aging people with mental retardation and found the majority had never before made contact with the mental retardation service system. These people were never on waiting lists. This is a problem that will likely grow, as families recognize the futility in many instances of trying to obtain services. There are also some families who choose not to seek services for their family member with mental retardation while they are living and can provide care.

Government at all levels must devote more financial resources to eliminating the waiting lists and other barriers to community services and supports. In addition to increased funding, creative usage of existing resources, including generic services, must also be explored to its fullest. Individuals with mental retardation and their families should drive the design of services and supports to assure consumer empowerment, choice and inclusion (The Arc, 1993).

Solutions in combating the waiting list problem lie in society's recognition of the severity of the situation for many families. More effort is urgently needed for solutions to meet families' needs. Here are a few examples of efforts already undertaken to find solutions.

- Many states use the Medicaid Home and Community-Based Waiver, which allows Medicaid to pay for community options for people who are in an institution or at risk of going to one. The waiver can be used to move people out of institutions. It can also be used to provide community residential services to people on the waiting list, particularly those with urgent needs. Waiver services typically cost considerably less than institutional services, allowing a state to serve more individuals.
- Several states have closed institutions or are in the process of closing institutions which enables them to serve more people on the waiting list. State leaders point out that institutional services are extremely costly. By closing institutions, many more people can be served. Oregon recently announced the closing of the Fairview Development Center by the year 2000. The state estimates $1.4 million in savings in 1998, $6.6 million in 1999 and $14 million thereafter which can be used to serve people from the waiting list.
- The Arc of New Jersey launched a media campaign titled "A Key of Our Own" to help the public and legislators understand the needs of families on the waiting list. As a result, the voters passed a bond issue to finance the construction of community residences.
- In Nevada, advocates succeeded in convincing legislators to fully fund the residential and day services waiting list in 1997 with funds for two years of growth in day services. An increase in family support funds was allocated to help any families entering the residential waiting list in the next two years.
- After an intensive grassroots family campaign called "A Key of Our Own: Unlock the Waiting List" sponsored by The Arc of Maryland and other advocacy groups, the state announced a five-year $68.4 million Waiting List Initiative aimed at finally addressing Maryland's waiting list. The Initiative includes funds in the governor's 1999 budget for day programs for all transitioning youth who exit school at age 21 and $5 million for emergency crisis placements.

To review The Arc report in its entirety, visit The Arc's web site at <http://thearc.org> Information on The Arc's *A Key of Our Own* campaign to focus attention on national waiting list efforts can also be found at this site.

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Current Trends in Providing Support for Families of Adults with Mental Retardation

BY TAMAR HELLER PH.D

The following article, which first appeared in the Fall 1997 issue of the newsletter, ALERT, is reprinted with the permission of the Institute on Disability and Human Development, University of Illinois at Chicago.

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• • •

"As I see it, you bring a child into the world, you're responsible for him. You have to set up care for as long as possible."

• • •

These feelings expressed by one mother who attended a meeting held at the Institute on Disability and Human Development last December, depict the feelings of many parents who provide lifelong care to their son or daughter with mental retardation. This article will present what we know about lifespan caregiving, families' needs for supports, and the latest trends in support services for families.

Life-Long Impact of Caregiving

Families of adults with mental retardation are their primary providers of care, with at least 80% of adults of all ages with mental retardation living at home. Many of these adults are not known to the developmental disabilities service system: estimates indicate that as many as 40% fall into this category. They come to the attention of providers when a parent dies and suddenly there are calls for emergency placements. These families have also been located when outreach is conducted through the aging network, which is often contacted first to address aging-related supports needed by the parents.

Because adults with mental retardation are living longer, families have a longer period of caregiving responsibility. For the majority of parents providing care, having their son or daughter living with them after he or she has reached adulthood is the preferred choice. **Families who have wanted out-of-home placements have often encountered long waiting lists or alternatives that were inadequate.** Older families become less able to provide care as parents and siblings deal with their own aging, careers, and other caregiving responsibilities.

Theories of lifespan caregiving

The developmental disabilities literature has tended to examine lifelong caregiving from a developmental perspective that takes into account the normative life stage tasks faced by families at different life phases. This suggests that as the child moves towards adulthood, caregiving becomes less normative, particularly if the child is still highly dependent on the parents. As the child gets older, the tasks and obligations of typical parenthood become more taxing and more divergent from normative roles. As children with mental retardation become adults, most continue to live with parents, unlike their peers without mental retardation. Hence, parents of adults with mental retardation are much less likely to experience an "empty nest" than other families.

In addition to fulfilling roles that are less normative with age, parents of adults with mental retardation are less likely to receive as much formal service support for their offspring as they did when they were children. **While there is federal legislation mandating educational services for all children with disabilities, there are no mandates for educational, vocational, or residential services for adults with disabilities.** Hence, in some families the parents are the sole providers for their adult son or daughter with mental retardation who may not be receiving any services or who may be on a waiting list for services. Furthermore, many of these adults lack friends and rely on their parent to meet their social and recreational needs.

Several studies which we conducted have suggested that older family caregivers perceive either less personal burden or a similar level than do younger caregivers. We found that with older age there appears to be greater acceptance of the family member and greater reciprocity in caregiving as the adult with mental retardation takes on caregiving roles with aging parents (Hayden & Heller, in press, Heller, Rowitz, & Farber, 1992, Heller, Miller & Factor, in press).

For example, in one of the families we interviewed a 50 year-old man with mental retardation was caring for a 90 year-old widowed mother who was incontinent and bed-

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ridden. A brother living nearby would check in on them. They were receiving no developmental disabilities services until the year that we met them.

The experience of raising a child with mental retardation can also lead to the development of new capacities and strengths that foster adapted responses. Some parents make a career of parenting and redefine the centrality of parenting as the major line of activity open to them, beginning to interpret it more positively. Over time, parenting can become a stronger source of self-meaning and purpose.

On the other hand, caregiving could be viewed as more stressful over time, if parents had aspirations that they were not able to achieve due to parenting responsibilities. This is particularly true for women, as they are much more likely than men to have given up a career to care for a child with a disability. Research has shown that only 8% of mothers return to work after having a child with a disability.

Future planning

Although families have strong preferences regarding the future care of their relative when they can no longer provide care, fewer than half of families actually make a plan for the future. The degree to which families plan depends on socioeconomic resources, personal coping styles, and the types of options available in their communities. For some families the topic is difficult to address, as they may not want to talk about death, or may fear stirring up anxiety among family members, particularly the adult with disabilities. Some families that struggle to get by have noted that they live one day at a time.

We have no money with which to plan. The lower your income, the stronger your faith in God. I live from day to day. I can't afford big dreams. I just hope to stay healthy.

Last year we started a futures planning program with 62 families at six sites in Illinois and Florida. We conducted training for families and support staff on legal and financial planning. We also conducted separate training sessions with the support staff, case coordinators and service provider agencies. The support staff were then instructed to follow-up with families on an ongoing basis. In a six month follow-up of the progress made by families in beginning to discuss and make future plans we realized that such planning is a long-term process that requires individualized approaches. Each agency used different approaches with varying degrees of commitment and resources. The most active agency followed up with regular phone calls and helped connect families to legal resources. We plan to follow-up in another year.

Role of siblings

In planning for the future the role of siblings needs to be considered. Siblings often become primary caregivers for their relative with mental retardation. As parents die, siblings often are expected to take over the responsibility, yet many are unprepared for the role and have rarely been included in family training efforts. Many families are ambivalent about whether they want this responsibility for their son or daughter:

I just don't want to put that burden on my daughter. It is one thing to expect a parent to love and care for their child; but it is too much to expect of one's other children.

A study examining actual placements over a three-year period following the death of parents found that in nearly one-quarter of the families the adult with mental retardation moved in with a sibling (Gordon, Seltzer, & Krauss, 1996). Even when the adult with mental retardation moved into an out-of-home placement, there was considerable sibling involvement, with many taking on the roles of guardian and advocate.

As families are expected to take on greater roles in providing care, siblings may face greater difficulties than parents in assuming such roles. **Given the vital role of siblings, the challenge to service providers is to form a partnership with them to support their ongoing involvement with their brother or sister.** (See related article on pages 25-27 of this *Newsletter*.) This necessitates that siblings receive information about services and supports and that service providers understand the preferences and capacities of siblings.

Family Support Interventions and Policies

As adults with mental retardation and their parents age, they likely face some functional declines and greater difficulty in maintaining independence. Yet, this group of families tends to be low users of services. Most of these families have been quite self-reliant in providing care for their children over the years. This section will describe their service needs and use, the importance of formal services in sustaining their ability to provide care, and different models of service provision.

Family needs and service use

Parents have been an undeniable resource for the service systems, and parents who provide a lifelong home for their son or daughter have made major contributions not only to their families but also to society. Families spend considerable out-of-pocket expenses for their adult relative with mental retardation living at home with them. A study conducted by Fujiura, Roccoforce, and Braddock (1994) indicated that families of adults with mental retardation spent an average of 20% of their pre-tax annual income on unreimbursed expenses for their adult relative.

As their children transition from childhood to adulthood, parents of adults with mental retardation face the unique challenge of dealing with their own age-related declines in health and energy and the decreased formal services available for adults with a disability. In order to maintain this living arrangement, parents report that their highest needs are for respite services, case coordination, and transportation. **Other key unmet needs reported by older family caregivers are for information regarding residential programs, financial plans, and guardianship and respite services. Also, they have major needs for advocacy and financial assistance.** In addition to needing services for their adult son or daughter with mental retardation, parents may also need services for themselves through the aging network.

Families often are unsure of appropriate goals and programs for their adult son or daughter and they may have reservations about using either the aging or

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developmental disabilities formal services system. Many older caregivers have not had formal services available in the past and express fear that placement is the main aim of the formal service system. For some families who have made a career of parenting, use of services reduces their roles and reduces their sense of purpose and identity. For example, some families may not be comfortable with a respite worker who comes in and helps their child gets dressed if that is a responsibility that the family has had for years. Other reasons why some families are reluctant to accept agency services are:

- Previous negative experiences
- Difficulties talking with providers who offer advice families do not agree with or who are not sensitive to their concerns
- Complex eligibility criteria for some services
- Inflexibility of services

On the other hand, some families may have been long-term users of services. They may have been active in developing parent organizations, support groups, or provider agencies. The service families are most likely to use for their child is day programming. While many families desire respite, frequently the public financial resources for respite care are insufficient to meet the demand.

Program Models

Several models of support interventions help families in sustaining care and in coping with their relative. These include:

- Support and psycho-educational groups
- Outreach through the aging network
- Family support programs

Support and psycho-educational groups

At least one fourth of the older family caregivers we interviewed expressed an unmet need for a support group (Heller & Factor, 1993). **Support groups are one type of intervention that can provide aging families with information, skills, and support for helping the adult with mental retardation, for helping themselves cope with the emotional aspects of caregiving, and for developing future plans.**

Smith, Majesky, & McCienny (1996) report that older families who participated in psycho-educational groups geared to caregivers of adults with mental retardation most valued the information on future planning and formal service and the opportunity to interact with other parents having similar concerns. Parents who did not live with their adult child with a disability reported benefiting the most from information on quality of residential programs. Although Smith reports family satisfaction with psycho-educational groups, few older family caregivers attend such events. Even when they would like to participate, older family members may have difficulty with transportation or scheduling. While these short-term interventions may ease stress or provide some needed information, they do not tend to have long-lasting impacts. Also, educational programs for caregivers can undermine the caregiver's own problem-solving capacity and sense of control over the situation.

Outreach through the aging network

Since federal legislation was passed that targeted collaborative projects between the aging and developmental disabilities networks, there have been several model projects that targeted elderly caregivers of adults with intellectual disabilities. These projects entail coordination, network building, and internetwork coalition-building between not only the aging and disabilities service agencies, but also other community agencies.

One example of such a project is the Hispanic Coalition Network that was developed in Chicago (Factor, 1996), which organized a Hispanic Fair that brought together 120 providers, elderly Hispanic family caregivers, and other community resources in a local community. In order to help attract the families, health screenings and food were offered. Many families who had not previously received needed services became aware and linked up with a variety of services.

Another example of a caregiver project is the New York Caregiver Assistance Project (Janicki, 1996). That project operated from a mode which assigned outreach and assistance functions to a host agency. Major components included a needs assessment, targeting of special households, and a program of promoting community awareness. The project found that area agencies on aging could provide a safety valve for potential crises that would have resulted in immediate placement demands and referral to possibly more costly developmental disability programs. Another major finding was that working with cultural organizations within the local community resulted in greater willingness of families to accept services.

Family support public programs

In the last two decades there has been a growing expansion of family support programs for families of persons with developmental disabilities. Most of the earlier programs provided discrete types of services that were directed by agencies and by professionals. These included primarily respite, counseling, and parent training services. Later, cash subsidies were added in some states.

However, with the emerging movement towards community empowerment and recognition of the need for persons with disabilities to remain in their communities and settings, new family-driven models have been promulgated. Generally, these more recent family support programs are based on the goals of strengthening family functioning and enhancing growth and development of individuals and the family. Ultimately, most of these programs have the goal of maintaining persons with disabilities within the family home.

As of 1995, 21 states had family support legislation. While there has been an increase in funding for family support programs in the last ten years, these programs represent a small portion of spending for mental retardation services. From 1988 to 1996 state expenditures for family support services increased from $171 millions dollars to $488 millions dollars. However, this amount only represents 2% of expenditures for mental retardation services and many of these programs only target children (Braddock, Hemp, Parish, & Westridge, in press).

Most of the innovative family support programs have developed models of consumer control in which

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families determine how resources are spent. These are based on the premise that families usually know best what it takes to maintain their relative with a disability in the family home. They also acknowledge the importance of using the informal network, including relatives, neighbors, and friends by allowing families to pay them for support services. To promote such flexibility, families may be offered cash subsidies to spend as they choose or, within certain parameters, vouchers to acquire various supports.

Most of the studies evaluating the impact of these family support programs have focused on families of children. These studies have documented their success in reducing stress and increasing life satisfaction for caregivers. In a study of a family support program in Illinois geared to adults, we found that family subsidies combined with service facilitation and consumer control of services and expenditures resulted in many positive benefits over a four-year period.

The Home-Based Support Services Program (HBSSP), administered by the Illinois DMHDD, was initiated in 1990 to assist adults (age 18 or over) with significant mental and developmental disabilities (or severe mental illness) to live more independently on their own or with their families. Participants are entitled to services up to $1,410 per month or $940 for those receiving Special Education services. The program was designed with the joint goals of improving quality of life for people with disabilities and reducing the cost of providing care for these individuals. It enables participants to exercise autonomy in choosing and obtaining support services or items. HBSSP participants choose a "service facilitator" who usually is a case coordinator or other agency personnel. He/she helps the participant devise a "service plan" or package of services and a spending plan for items the participant wants to purchase. The plan may be revised monthly.

Findings from our evaluation study of the program (Heller, Ruch-Ross, & Kopaick, 1995) indicated that for adults with developmental disabilities the program resulted in the following:

- The top services used in the program include respite care, transportation, vocational services, social recreation services, and dental care.
- In comparison with families who did not receive these services through a lottery selection process, the participant families reported fewer unmet service needs, greater satisfaction with services, greater caregiving satisfaction, and greater feelings of competence and self-efficacy in helping their relative with developmental disabilities. In addition, participant families reported less need for out-of-home placements (13% versus 27%) and were more likely to engage in legal (68% versus 53%) and financial planning (55% versus 42%) for their relative.
- In addition, benefits included more community integration and improved interpersonal relations for the adult with developmental disabilities.

We also estimated that the program results in cost savings to the state. Over 27% of the families interviewed noted that without the program they would need to find an out-of-home placement. **In FY 95 the average annual cost for the Home-Based Support Services Program (HBSSP) per participant with a developmental disability was $10,668. Out-of-home annual residential costs would have ranged from $17,362 for a Community Living Facility to $75,091 for a state developmental center.** While this program has many benefits for its participants, its demand far exceeds the number of people that the program has been able to serve.

With the trend to community inclusion and consumer control of resources, and pressures to cut costs by reducing residential services, there is likely to be an increase in family support programs. For older family caregivers this can result in added resources for maintaining caregiving within the family. However, with the advent of managed care there is the danger that the funds will be too small or that sufficient residential options will not be in place for those families not able to provide care in the home setting.

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Kenneth and Leslie Moore

Oh Brother! Siblings Need Support

BY KENNETH MOORE

Across the country, advocates for people with disabilities and their families have been launching a crusade to attack the problem of the lengthy waiting lists people with disabilities must climb in order to receive residential, day/vocational, or a variety of other necessary services. In Maryland, the state waiting list for such services, sometimes called the "death and dying list," is approximately 5,300 (Pierre, 1998) people, while the national waiting list is estimated to be approximately 218,000 people, which does not include individuals living in state institutions who are waiting for community placement (Davis, 1997).

Parents of people with disabilities often speak about wanting to ensure that the needs of their children with disabilities will be met by states after their death. Parents hope that their burden in raising their children with disabilities won't be inherited by siblings who are trying to create lives of their own. In an ideal world, such wishes should be strived for. However, in reality, siblings are often the ones to take on much responsibility for their brothers and sisters with special needs.

Much has been written about the needs of individuals with disabilities both before and after the death of a parent or parents. But what about the needs of their siblings? What challenges do we siblings face after the death of our parents? What supports do we need as well?

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In reality, siblings are often the ones to take on much responsibility for their brothers and sisters with special needs. Much has been written about the needs of individuals with disabilities both before and after the death of a parent or parents. But what about the needs of their siblings? What challenges do we siblings face after the death of our parents? What supports do we need as well?

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I am the younger brother of an adult woman with multiple physical and developmental disabilities and a chronic serious migraine disorder. Through my experience growing up with Leslie, I have often felt from an early age that the lives of siblings of people with disabilities will always be significantly different than the lives of our same-aged peers who do not have a brother or sister with special needs. We siblings simply face added responsibilities throughout our lives. That responsibility might include helping our parents cope with the constant demands a brother or sister with disabilities places at home, or it might simply be defending a brother's or sister's honor at school or in the community. No matter how much our parents try to keep us siblings from feeling their parental responsibility or from feeling burdened by our siblings' needs, I believe it is only natural that we siblings do feel an imposed obligation. Because of this, we siblings might bond closely with our brothers or sisters and take on extra responsibility in becoming their advocates. Other times, we may shun the burden and may start spending more time away from home. Sometimes, siblings might decide not to help at all.

Issues of involvement and responsibility become significant, once again, after the death of our parents. Even if one parent is left remaining, many siblings begin to realize that at some point they will, ultimately, be the last remaining familial connection to their brother or sister — the last connection who witnessed and played a role in all of the siblings' challenges, difficulties and accomplishments growing up. Even when the best of schools, public and private agencies, and professionals have been placed around a brother or sister's system of care, a sibling will still be the only person left bonded to the person with disabilities because of familial heart and history rather than paycheck duty. This is a heavy responsibility, both emotionally and practically, for a sibling, whether he or she is in his '20s and just beginning to make important life decisions for himself, or whether he is older and settled, perhaps even raising children of his own.

We siblings need to know that services established to meet our brothers' or sisters' needs will also be there to meet our own. Those of us siblings who are involved in the lives of our brothers and sisters need assistance in tackling our new roles as the primary family support, especially since our lives will change drastically after parents die. We would be helped if the system of care from the adult service world established a mecha-

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nism for welcoming us, for providing outreach so we would know where to turn, for educating and coaching us through our new roles, and for facilitating our involvement with service providers. Visible and accessible peer/sibling support groups should also be available to us should we want support in adapting to our new roles and responsibilities.

Some of us who are already advocates need support so we can fully comprehend the complexities of adult services — the Individualized Team Meetings, the Social Security issues, trust funds, managed health care, future planning and, most significantly, the daily challenges that may seem small but take away mountains of time. Others who haven't been as involved might be searching for help, too. These cases might even be more difficult, since there may be difficulty accepting the demands of becoming a primary advocate for a brother or sister with disabilities. The role will be different, and the siblings might even need help in learning how to re-connect with a brother or sister who may have caused years of anguish and resentment in the past.

Regardless of past history and present circumstance, all of us need to be supported in any role that we can play. Support from professionals in the adult service world needs to be available to help maximize our participation in our own siblings' lives no matter how intensive or minimal our involvement might be. Professionals shouldn't quickly assume that they are the ones to take over all the responsibilities and the choices for our siblings' lives once a parent dies. We siblings might have more insight into certain situations and may want to advocate for our brothers and sisters. However, professionals also shouldn't assume that a sibling will be able to be a big force in his or her sibling's lives. Some siblings may not be ready or able to carry the responsibility. Each one of us will have a different relationship with our respective brother or sister. No matter how much each one of us decides to be involved, what we all need to be able to live our own lives with peace of mind is the security that our brothers' and sisters' needs will be met even at times when we might not be around.

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> *We would be helped if the system of care from the adult service world established a mechanism for welcoming us, for providing outreach so we would know where to turn, for educating and coaching us through our new roles, and for facilitating our involvement with service providers.*

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Leslie (r) and her mother, Cory

I grew up involved with my sister. My mother used to tell me that Leslie taught me the beginnings of life. I learned quickly that there were things that I had the ability to do that she couldn't and would never be able to do. And, because of that, I took on the job of becoming my sister's helper, sometimes with pride and sometimes with resentment. Over the years, our relationship strengthened with a strong sibling friendship. My role seemed natural to me. I was somewhat like an older brother despite being three years younger.

But it was my mother who was there to create the vision for Leslie's life and to work and fight to make sure that the school system, agencies, and community understood and executed her ideals for her daughter's inclusion into the fabric of our community's life. My mother fought the battles. She knew how to deal with the setbacks, the problems, and the people that stood in front of Leslie's path to happiness and independence. When she heard professionals tell her all the reasons why Leslie would never be able to hold a job in the community or live semi-independently in an apartment — which she now does — my mother learned how to maintain the clarity of her dream for Leslie despite shaking with her own uncertainties and fears.

One of the hardest problems I faced in taking on the responsibility for guiding Leslie to continued growth is that my mother would have been the person I would have sought advice from regarding Leslie. No longer is she here to talk to me and help me understand what to do in order to be the best guide for my sister. And, no matter how much my mother prepared me and Leslie for her inevitable death, there wasn't any blue print that she could have left for me and Leslie to follow.

I do know that my mother worried that I would feel the burden of Leslie's needs. She feared that obligation would be imposed upon me, and as she planned for Leslie's future, she made sure that I recognized my independence and had the outlets to create my own life. During her illness, she did her best to ensure that there would be supports available to me and to Leslie. She didn't want my life to be compromised because of Leslie.

But, there is something much more powerful that my mother planted long ago which has perennially bloomed in our family's garden. She made Leslie a

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I do know that my mother worried that I would feel the burden of Leslie's needs. She feared that obligation would be imposed upon me, and as she planned for Leslie's future, she made sure that I recognized my independence and had the outlets to create my own life . . . . . . She didn't want my life to be compromised because of Leslie.

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true part of the family. She facilitated the love between us and the sense of responsibility and familial love that should be there among siblings. And, by letting the relationships grow naturally and where they were meant to go, she gave me the sense of enjoyment that one feels when he or she experiences the pride in watching a loved one grow. I am not only a part of my sister's life. She is an integral part of mine, and because of that, I made the choice early on that I would be there for Leslie should anything ever happen to my parents. After my mother died, I just needed help in learning how to best cope with and handle the new responsibility I had chosen to undertake.

As a sibling, I implore parent information centers across the states to build sibling wings as part of their centers and to guide us siblings of people with disabilities in building a network with other siblings, thereby giving us access to others for sharing support and technical assistance through the crises and through the daily challenges of everyday life. Across the states, parent information and training centers have been established to assist parents of children with disabilities. Here, parents can seek the input, assistance, and emotional support from other parents, parent educators, and advocates, and know they have a safe place to voice struggles, hopes, fears, and dreams. We siblings, especially those of us who choose to be heavily involved after a parent dies, assume responsibilities that parents would typically handle. We need a place and people we know we can turn to rather than battling so many issues on our own.

Throughout our lives, we siblings of people with disabilities have seen how much support our brothers and sisters have needed. Because of their needs, we have also witnessed how much attention and support they have received, sometimes even at our own expense. By adulthood, roles have already been developed in families due to familial patterns and history. Many of us siblings will choose to carry on the work our parents accomplished in making the rest of our sisters' and brothers' lives full and meaningful. Many siblings will not be ready or able to become advocates — some siblings may not even reside in the same state as their brother or sister.

What all of us siblings need from the adult service system, from parent information centers, and from sibling/peer support groups after parents die is support and guidance in any role we choose to or will be able to play in the lives of our brothers or sisters. Whether the role we will play in our siblings' lives will be daily and intensive, kept to an occasional visit, or is somewhere in between, we siblings need support, too. In the long run, if service providers, public and private agencies, and professionals take time and effort after our parents die to assist us and include us in their process of meeting the needs of our brothers and sisters, we all will have much to gain.

Ken and Leslie (1986)

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Ken Moore is a freelance writer in Bethesda, Maryland, and co-author of The ADA and People with Mental Illness: A Resource Manual for Employers. He is currently working on a manuscript entitled Who Will Be My Mother?, a book that will share his and Leslie's story. Mr. Moore begins his graduate studies in the fall at Catholic University in Washington, D.C. in the social work field. Questions about this article or requests for information on sibling supports can be directed to Mr. Moore at 301-468-0940.

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"THIS IS STILL A WORK IN PROGRESS": COMMON GROUND, LITTLETON, NEW HAMPSHIRE

PAM WALKER AND MAIR HALL

Common Ground is committed to the belief that those we serve have the right to fully experience life. It is our role to assist the community in supporting each of its members along their journey.

Introduction

Nestled in the picturesque town of Littleton, in northern New Hampshire, is the program Common Ground. The program, as it is now organized, is 3 years old and supports 52 people with developmental disabilities, including some with significant and multiple impairments, in a broad range of individualized, integrated daytime activities, including supported and competitive employment, self-employment, volunteer work, and the pursuit of recreation/leisure activities. This report is based on a 3-day visit, in April of 1997, to Common Ground. The purpose of our visit was to document innovative, integrated daytime supports for people with developmental disabilities, focusing on those directed at assisting people in community involvements other than or in addition to supported or competitive employment.

Common Ground: Organizational Structure

Common Ground, located in Region I of New Hampshire's service system for people with disabilities, is one of a number of programs that compose White Mountain Mental Health and Developmental Services (WMMH+DS). Common Ground employs five full time team leaders who coordinate the work of a group of part-time Community Integration Specialists (CISs). Together, team members are responsible for the provision of daytime support for 7 to 12 individuals. CISs use their own cars, for which mileage reimbursement is received. They support people on an individualized basis as well as in small group activities. The availability of some one-to-one support for everybody allows each person the opportunity to pursue individualized connections and involvements. One team leader described the advantage of having the staffing available to provide one-to-one support, as follows:

> *We used to have to think, if you found one person who wanted to go skiing, OK, do we have three other persons to go skiing? Now, we can just go do it with one person.*

The Creation of Common Ground

Before Common Ground was created in 1994, the agency operated two sheltered workshops. As the Area Director put it:

> *It was clear that we had a facility-based system that we were trying to stretch to provide community-based supports and services. We had a building that got in the way. Due to our staffing pattern, we couldn't figure out how to do community integration except in groups of people.*

It was clear to her that the workshop system, which had once been viewed as "cutting edge," was not capable of providing appropriate community opportunities. So, she began a reorganization within the agency to create the Common Ground program. Originally, there were 25 full time staff for the workshops. All of the staff positions were readvertised with only five full time positions (team leaders); the rest were part time. She wanted people who could work flexible hours and who were "connected with the community." The agency discontinued the use of vans to drive groups of people around the community. Most people now travel in staff cars, with reimbursement for mileage paid to staff. For those who need them, there are wheelchair accessible vans.

Support for Meaningful Days in the Community

A number of people at Common Ground are involved in supported or competitive employment for several hours of their week. However, agency staff have also assisted people to pursue other paid work options, such as starting their own businesses. In addition, they do not aim exclusively toward paid work as the single most meaningful involvement; rather, they look more broadly to supporting people in a wide variety of integrated day activities, based on personal interest, that promote meaningful and valued roles in the community. This may involve any combination of activities including supported or competitive employment, self employment, volunteer work, leisure activities, community connections, advocacy, and so on.

The program has supported a few individuals to start their own businesses, some under the auspices of the program and some fully independent of it. For instance, Stephanie has a mailing and collating business. For the time being, she has chosen to operate it from space within the agency office building. Eventually, she would like to have her own space, once the business is going and she has accumulated enough funds to pay for rent and a support person. During our visit, Stephanie was in the midst of doing an 10,000-piece mailing for the Littleton Chamber of Commerce; she is also a member of the Chamber and they help to advertise her business. She has enough work at this point that she may be looking to hire an assistant in the near future.

Steve has a delivery service, selling bagels, doughnuts, and other snacks at

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local businesses, as well as taking lunch orders by fax, picking them up, and delivering them. His business is fully independent of Common Ground. Steve receives waiver funding, which covers support staff for him. Steve's mother has chosen to directly receive all of the support money for Steve. She did this for a few reasons. After Steve graduated from school, she had helped arrange a job for him doing deliveries in a hospital, but she felt he was isolated in his work there. In addition, she had seen many other young people who had gone from high school into various employment programs, and she wanted something different for Steve.

Most of the people whom the agency supports in paid employment do not work full time. These people sometimes choose to do volunteer work in addition to paid employment. Others who do volunteer work do not have paid employment. However, the agency does not view volunteer work as a substitute for paid work. They are committed to increasing the opportunities for paid employment for people they support, and have directed resources to this effort (e.g., the creation of the job development position).

At the same time, work--whether paid or volunteer- does not fill up the whole day of most of those supported by Common Ground. Helping people to spend their remaining daytime meaningfully can be a challenge. In a small rural town, where neighbors may be few and far between, and winter snows make road travel enormously difficult, establishing community connections is not always easy. Staff at Common Ground recognize this difficulty and have put significant effort into helping find meaningful connections and experiences.

For example, Scott always wanted to be an actor. In fact, his mother says that while in high school before he became disabled he often talked about dropping out of school and becoming an actor. Since Scott still talked about wanting to act, Ellie, his CIS, helped him get a part in a local community play. She supported Scott to act in the evening practices and performances. Because Maggie, who has severe and multiple disabilities, went to her local school, many people in the community already know her. However, before her involvement with Common Ground, other than school, she rarely spent time in the community. Now, she skiis, swims at the local health club, and enjoys eating out, among other things.

Lessons and Challenges

As they have pursued the development of innovative practices in supporting people to have meaningful daytimes, staff at Common Ground have discovered new challenges.

- **Need for new staff roles: Reliance on the community, not a facility.** By closing their sheltered workshops and creating a totally new program focused on community integration, Common Ground has allowed for the individual daytime support of each and every person that they support. Since the closure of the workshops and the establishment of Common Ground, staff have not had the option of turning to a facility if and when problems arise in the community. Staff have had to learn to rely on community members to be involved in relationships and supports. This shift, toward involving the community, feels better to many of the people they support and their families. Staff agree that not having the facility pushes them all to be more creative and come up with new solutions and strategies for support. As one team leader put it, "It is not OK to just be doing custodial care in the community."
- **Change involves trade-offs which may bring both advantages and disadvantages.** In order to free up the budget to support people in individualized ways in the community, the Area Director reduced the number of staff and the pay and benefits to many staff. While there are many advantages from the new, more individualized staffing for the people they support, at the same time, the disadvantage is that they cannot offer full benefits to part-time staff and they have not always been able to retain good staff people who have desired or needed full-time work and comprehensive benefits. This is a direction that many other agencies would not choose to go. However, this example points to a dilemma faced by many agenciesóhow to increase individualized staff support and at the same time support staff well. Agencies should not have to be in a position where they feel that the only way to provide individualized support is to reduce staff benefits. As such, a challenge for states is to provide resources and incentives that enable agencies to both provide individualized support and at the same time offer staff comprehensive benefits. For its part, Common Ground is committed to seeking the means to offer full-time work and/or comprehensive benefits to more of their staff.
- **Roles and relationships require shared community places and experiences.** In order for roles and relationships to occur, people must spend time with other community members. However, especially for the younger people supported by Common Ground, many of their peers without disabilities are working. Thus, for those they support, whether in work or other activities, Common Ground strives to help them participate in settings that offer opportunities for interaction with peers.

It is especially challenging to figure out how to assist those who live in isolated, rural communities to expand their experiences and social networks. For some people, it may involve significant travel time to connect with others for desired activities; for others, it may involve seeking out what connections are possible within their immediate, rural locality. As one illustration, staff related the story of a man named Joe, who lived a very isolated life in a very rural area and never came to the program at the workshop. According to staff, Joe only said a few words, one of which was "wood." They knew that he loved chopping down trees and doing other work related to wood. At first, staff assisted Joe, with a loan from the program, to buy wood to split and sell. However, over time, what they have found works better for Joe is to take on small jobs of cutting wood for other community members as needed. Thus, since the creation of Common Ground, staff have been able to support Joe to both do some work he enjoys and to have contact with other community members, within this very rural area. On the other hand, while Steve's business provides some community connections for him within their rural

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area, his mother is still concerned about his lack of relationships beyond his family, since he finished school. She is not sure what is the best approach to helping him expand his social network, and is debating whether the family should move to a larger community.

Conclusion: Thinking About the Future

In thinking about the future, staff at Common Ground feel it is important to remain flexible. It is the belief of staff at Common Ground that there are many different ways to create valued roles in the community. Based on this, they have significantly expanded the options available to the people they support. In their journey to do so, they hope to avoid getting locked into specific ways of doing so, and thus remain open to continual evolution and learning. As they put it, "We need to constantly look at and challenge what we are doing so we don't get locked into things again. This is still a work in progress."

All names used throughout the report are pseudonyms.

This article is based on a longer site visit report on Common Ground, which is available from the Center on Human Policy. To receive a copy write to:

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In Memory of Paul Hearne 1949-1998

It is with the deepest sadness that we must, once again, report the tragic loss of another of our leaders in the disability rights arena. "Unity, Leadership and Impact . . ." express the goals and achievements of Paul Hearne, president of The Dole Foundation for Employment of People with disabilities and president and CEO of the American Association of People with Disabilities. Hearne, one of the nation's foremost civil rights leaders and advocates, died Sunday, May 3rd at his home in Arlington, Virginia from complications due to pneumonia. He was 48.

As president of the Washington D.C.-based Dole Foundation for Employment of People with Disabilities, Paul put a spotlight on the importance and value of employment as the key to participation and independence for people with disabilities. From his personal experience with disability (he was born with osteogenesis imperfecta, a connective tissue disorder causing his bones to imperfectly form and break frequently), Paul knew first hand the discrimination and struggle to gain viable participation, education, employment and legal rights for people with disabilities.

Paul's life was a series of "firsts."

- He was one of the first students at Long Island's Human Resource Center (one of America's first schools to provide a real education to young people with significant disabilities).
- He was the first person with a disability to graduate from Hofstra (New York) Law School.
- He established the first dedicated legal services office for people with disabilities.
- He was one of the nation's first disability employment experts and one of the first disability advisors to the New York State Legislature and Department of Education.

As executive director of Just One Break (JOB) in New York City from 1979 to 1988, Paul established his leadership in the employment arena and wrote the employment sections of the first national legal handbook for attorneys on disability law in 1980. From 1988 to 1989, as director of the National Council on Disability in Washington D.C., he helped draft and press for the passage of the Americans with Disabilities Act (ADA).

In 1989, Paul was asked by Senator Robert Dole to head his foundation on employment of people with disabilities in Washington, D.C. For the past ten years, Paul used his talents to raise over $15 million in funds for The Dole Foundation, which provides grants for local employment programs throughout the country.

His vision for full participation of people with disabilities was brought to realization with the new organization, the American Association of People with Disabilities (AAPD). Paul, along with four other key leaders of the disability community created AAPD -- a national non-partisan coalition that represents America's millions of citizens with disabilities. His vision included access to basic benefits often denied people with disabilities. He believed that AAPD would answer the need for all people with disabilities to access consumer and economic power and provide a unified purpose and message to achieve full inclusion in America.

Upon hearing of Hearne's death, Senator Dole said, *"Paul is a dear friend who will be greatly missed. As president of the Dole Foundation, he dedicated his career to insuring that individuals with disabilities had full, meaningful participation in everyday life. Paul leaves a legacy of national leadership through the American Association of People with Disabilities."*

Paul is survived by his mother, Mrs. Patricia Hearne, one sister, Ms. Jennifer Hughes, a brother-in-law, Mark Hughes, one nephew who was also his godchild, Aiden Peter Hughes and his wife, Pamela Hearne of New York, NY.

In lieu of flowers, donations may be made to: AAPD, 1819 H Street, NW, #330, Washington, DC, 20006 or Osteogenesis Imperfecta Foundation (O.I.F.), 804 W. Diamond Avenue, Suite 210, Gaithersburg, MD, 20878.

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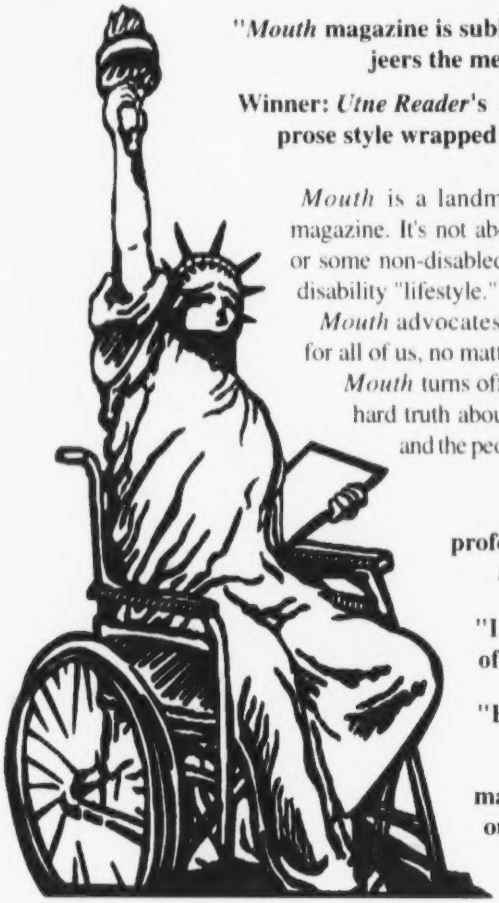

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TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

Liz Healey, *President*
Mark Partin, *Vice President*
Doug Biklen, *Chair of the Executive Committee*
Joe Wykowski, *Secretary*
Mike Auberger, *Treasurer*
Nancy Weiss, *Executive Director*
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Barbara Buswell
Donna Gilles
Lori Goetz
Robert Holland
Michael Kennedy
Jay Klein
Tim Knoster
Deb Kunz
Frank Laski
Liz Obermayer
Linda Rammler

MEMBERSHIP INFORMATION

Referred by:

Name: ____________________

Address: ____________________

City/State/Zip: ____________________

Telephone: (   ) ____________ Fax: (   ) ____________

E-mail: ____________________

Is the above your
work address   home address
other ____________

Please Check Appropriate Categories
(not more than three):

( ) Administrator/Adult Services
( ) Administrator/Education
( ) Administrator/Other
( ) Adult Service Provider/Staff
( ) Behavior Specialist
( ) Case Manager
( ) Early Childhood Services
( ) Educator/Teacher
( ) Gov. Personnel (Federal, State, Local)
( ) Interested Individual/Advocate/Friend
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional Public Policy Advocate
( ) Professor/Instructor (College/University)
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
( ) Student (College/University)
( ) Supported Employment/Day Personnel
( ) Other

Moving?
Please notify TASH of your new address.

General Membership (individual)	$88
Agency/business/university/college/library/school (allows 3 conference attendees at the member rate)	$200
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship)	$45
Family (group rate)	$136
Lifetime Member	$1000

Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada. Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank.

If you would like to charge your membership, please fill in the necessary information.
( ) Mastercard ( ) Visa ( ) Discover

Card Number ____________________

Expiration Date ____________________

Signature ____________________

( ) I would like to arrange to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

If you are applying for a student membership, please provide the following information.

Department ____________________

College/University ____________________

Student I.D. Number ____________________

Anticipated year of completion ____________________

( ) Add $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone: 410/828-8274 Fax: 410/828-6706

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Address Correction Requested

MAY 1998

PRINTED IN THE U.S.A.

Newsletter

URGENT!
Dated Material
Inside!
TASH Board
Election Ballot

MULTICULTURAL & INTERNATIONAL PERSPECTIVES

Native American Communities: A More Inclusive Society? (U.S.)

The Independent Living Movement in Latin America (Brazil)

People with Disabilities Involved in International Development (Vietnam; Micronesia)

***A Study of Minority Women* (Iceland)**

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 105 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

From the Executive Director

BY NANCY WEISS

In this issue of the *Newsletter* you will find a ballot for new Executive Board candidates. Please take a minute to complete it. TASH is not the office in Baltimore or the organization's staff. Rather, TASH is its members, chapters and committees, all of which are represented by a Board of fifteen members, elected by the membership. The only way to make the Board a truly representational body is to have a broad range of members shape the make-up of the Board by voting.

We have begun sending out member survey forms when we mail membership cards. We have gotten hundreds of responses and I have reviewed all of them. Most people are pleased with TASH's work and especially value the *Newsletter*, the Journal, the conference, the legislative updates they receive and our grassroots advocacy. The survey asks people what topics they would like to see covered more often in our publications and conferences. The responses to this question vary greatly but can be divided into two categories — those that say, in essence, TASH should return to a clearer focus on the needs of people with the most significant developmental disabilities and those that urge TASH to become a broader, multi-disability advocacy organization. In addition, some respondents welcome the broader focus on early childhood issues, adult issues, and issues of aging while others would like to see a return to a focus on children and educational issues.

Continued on page 3

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail dmarsh@tash.org
- **For questions about the 1998 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail knelson@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail mroth@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions or advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail pnewton@tash.org
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

From The Executive Director

Continued on page 2

This may be a good time to take another look at TASH's Mission Statement and ask the questions that every organization should ask of itself on a regular basis. These questions include: What is TASH's purpose?; What makes it unique and important among other disability organizations?; and, Where should TASH, as an organization, focus its energies in the coming years? The following is TASH's mission statement:

Stretching the boundaries of what is possible:

- Building communities in which no one is segregated and everyone belongs;
- Forging new alliances that embrace diversity;
- Advocating for opportunities and rights;
- Eradicating injustices and inequities;
- Supporting research;
- Promoting inclusive education for all;
- Disseminating knowledge and information;
- Supporting progressive legislation and litigation, and;
- Promoting excellence in services.

I'd like to hear from members about our Mission Statement. Is it still fresh? Does it continue to convey what TASH is about at its core? Does it provide clear guidance with regard to the directions in which TASH should be focusing its energies?

A mission statement, of course is just that – a statement. A good mission statement reflects the core values and directions of an organization but the real questions are:

- What are the issues on which TASH should be focusing? and,
- What should distinguish this organization from other disability organizations?

TASH is unique in that it is not a professional organization, nor is it a parent or a self-advocacy organization. Rather, it is a true coming together of people from a range of walks of life who are tied together by a common set of values and beliefs. It is this shared vision that makes the organization strong.

I'd like to bring together a small group of members (including chapter representatives and Executive Board members) to take a look at TASH's mission and mission statement. Please contact me if you have thoughts about the issues raised above and/or if you would have interest in participating in this small group. I can be reached by phone (410-828-8274, ext. 101); e-mail nweiss@tash.org, or fax (410-828-6706).

1998 TASH Annual Conference

Take time to experience the taste, sights and sounds that have made Seattle one of the premier convention destinations in the country! Check out one, or both, of these exciting tour events during your stay in Seattle.

Grapes & Hops Tour

Enjoy the scenery of rural Seattle as you travel to the Columbia Winery and Redhook Brewery. First, you tour charming Redhook Brewery. Try several complimentary hearty microbrews, while learning the beer making process and the history of the Redhook Brewery. You'll receive a Redhook Brewery souvenir glass during the tour.

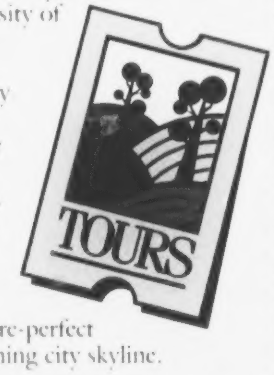
Next, tour the spectacular Columbia Winery. You'll discover Columbia Winery's history and how this winery produces such award-winning wines. After the tour, enjoy complimentary wine tasting - a feast for the senses.

Date: Saturday, December 5th; tour departs at 2:00 PM
Duration: Approximately 5 hours
Cost: $42.00 (includes a box lunch)

Seattle City Tour

You will learn why Seattle has been named one of America's most livable cities! Our friendly and informative tour guide will give historical background on the area, point out interesting landmarks, as well as give insider tips on special shopping and sightseeing areas.

Included in the tour is Freeway Park and the bustling Pike Place Market where Seattleites shop for produce and art. You'll see historic Pioneer Square which was settled in 1852 and is now home to Seattle's top art galleries; the International District, heart of Seattle's Asian community; and the magnificent gothic-style buildings on the 680-acre University of Washington campus.



Next, explore the Hiram Chittenden Locks, the passageway between saltwater and fresh for 78,000 vessels a year. Inspect the fish ladders where thousands of salmon travel upstream to spawn. Visit a local coffee roasting plant and learn all about coffee roasting. Finish your tour at one last stop - Magnolia Bluff neighborhood - north of the city, for picture-perfect views of Elliott Bay and the stunning city skyline.

Date: Sunday, December 6th; tour departs at 9:00 AM
Duration: Approximately 3 hours
Cost: $28.00

Creating Futures Together

TASH Conference '98

SEATTLE, WASHINGTON

Tentative Conference Agenda

Tuesday, December 1, 1998

8:00 AM - 10:00 PM	Registration Open

Pre-Conference Activities
Wednesday, December 2, 1998

7:30 AM - 8:45 AM	TASH Tech Registration
8:30 AM - 4:30 PM	Club TASH Day Care/Youth Activities
9:00 AM - 4:00 PM	TASH Tech Workshops
9:00 AM - 4:00 PM	TASH Chapter Development and Leadership Training
2:00 PM -8:00 PM	TASH Conference Registration
5:00 PM -7:00 PM	Opening Reception in the TASH Exhibit Hall

Thursday, December 3, 1998

7:30 AM - 1:00 PM	Registration
7:30 AM - 3:00 PM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 3:15 PM	Conference Sessions and Poster Presentations
3:30 PM - 5:30 PM	Plenary Session
5:30 PM -7:00 PM	No-Host Reception

Friday, December 4, 1998

7:30 AM - 11:00 AM	Registration
7:30 AM - 3:00 PM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 3:15 PM	Conference Sessions and Poster Presentations
3:30 PM - 5:30 PM	Plenary Session
5:30 PM - 7:00 PM	No-Host Reception

Saturday, December 5, 1998

7:30 AM - 9:00 AM	Registration
7:30 AM - 12:00 PM	TASH Exhibit Hall Open
8:30 AM - 1:00 PM	Club TASH Day Care/Youth Activities
8:00 AM - 12:45 PM	Conference Sessions and Poster Presentations

1998 TASH KEYNOTE SPEAKERS

We have exciting and varied keynote speakers this year. Some brief preview information about the speakers is listed below. Check out the next issue of the *Newsletter* or the conference brochure for more complete biographies and pictures!

Thursday, December 3, 1998

James Banks

James is a Professor of Education and Director of the Center for Multicultural Education at the University of Washington. He is a past President of the American Educational Research Association and a past President of the National Council for the Social Studies.

Sue Rubin

Sue is a self-advocate diagnosed with autism and moderate mental retardation. Currently she is a student at Whittier College and a consultant at WAPADH, an agency that supports adults with developmental disabilities, where she demonstrates facilitated communication at monthly trainings.

Robert Williams

Recently appointed by President Clinton, Bob is the Deputy Assistant Secretary for Disability, Aging and Long Term Care Policy in the Office of the Assistant Secretary for Planning and Evaluation.

FRIDAY, DECEMBER 4, 1998

Duane French

Duane is the first person with a significant disability to be appointed as a Division Director with the State of Alaska. Prior to his appointment as the Director of the Division of Vocational Rehabilitation, Duane was the Executive Director of Access Alaska. Duane most proudly describes himself as a brother in the disability rights movement.

Laura Hershey

Laura is a disability rights leader, poet, writer, and trainer. She educates and agitates whenever possible to promote the rights of people with disabilities. She has organized social change campaigns and events around issues such as Social Security work disincentives, economic justice, disabled women's leadership development, and opposition to charity telethons.

Judith Heumann

As Assistant Secretary of Education for the Office of Special Education and Rehabilitative Services, Judith manages the Office of Special Education Programs, the Rehabilitation Services Administration and the National Institute on Disability and Rehabilitation Research.

Zuhy Sayeed

Born in India, Zuhy moved to Lloydminster, Canada in 1978 where she began her career in early childhood education. As parents, Zuhy and her husband Raffath became active in the field of differing abilities in 1982; today their dedication to human rights and community living is a family commitment.

Creating Futures Together

TASH Conference '98

SEATTLE, WASHINGTON

1998 TASH
Conference Registration Form
Creating Futures Together

Seattle, December 2-5, 1998

Mail form to: TASH
29 W. Susquehanna Avenue, Suite 210, Baltimore MD 21204-5201
Fax form to: 410-828-6706
Questions? Call 1-800-482-TASH

The registration form can also be found at our Web site at www.tash.org
You may use this form to register for the conference, become a TASH Member, or both!

Please Print

First Name ____________ Last Name ____________
Preferred Badge Name ____________
Agency/School/University ____________
Mailing Address ____________
City/State/Province ____________ Zip/Postal Code ____________ Country ____________
This address is: home work school other ____________
Billing address (if different from above) ____________
Agency/School/University ____________
Mailing Address ____________
City/State/Province ____________ Zip/Postal Code ____________ Country ____________
Daytime Telephone ____________ Work Telephone ____________ Fax ____________ e-mail ____________
This address is: home work school other ____________

Please circle the appropriate numbers that describe your affiliation (not more than 3):

1. Administrator/Adult Services
2. Administrator/Education
3. Administrator/Other
4. Adult Service Provider/Staff
5. Early Childhood Services
6. Government Personnel
7. Legal Services Provider
8. OT/PT
9. Parent/Family Member
10. Professional/Public Policy Advocate
11. Professor/Instructor (College/University)
12. Psychologist
13. Regular Education Teacher/Admin.
14. Related Services Provider
15. Self-Advocate
16. Social Worker
17. Speech/Language Pathologist
18. Special Ed. Teacher/Support Spec.
19. Staff Development/Trainer
20. Student
21. Supported Employment/Day Personnel
22. Other ____________

Please fill out this section only if you are registering for the conference:

TASH Membership: I am a current member Individual Agency
Membership# ____________
If you are a student member, please list your Student ID# ____________
I am becoming a member now *(please be sure to enter the applicable cost on the reverse side)*
I am renewing my membership now *(please be sure to enter the applicable cost on the reverse side)*

Optional Conference Information Requested (please request by October 16, 1998)

Accessibility Details
Sign Language Interpreter
Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited and there is a nominal fee.)
Roommate Referral Program
List any accommodation needs ____________

Application for CEU credits have been made to the following organizations:

National Association of Social Workers, American Physical Therapy Association, The American Occupational Therapy Foundation, American Therapeutic Recreation Association and local education agencies.

I would like to request further information on CEU credits List Type ____________

To Become a TASH Member or Renew your Membership NOW. . .

You may also use this form to become a member at the same time you register for the TASH conference! This allows you to register for the conference at the reduced TASH member rate (see other side for member registration rates) or, *use this form to join as a member without registering for the conference.*

Membership rates are listed below. Determine the appropriate membership category, be sure to fill in the applicable rate on the reverse side of this form when entering payment information, and include payment at the time you submit your conference registration payment.

General International Membership (individuals) $88.00
Agency/Business/University International Membership .... $ 200.00
Self-Advocate, Parent, Full-Time Student $45.00
Family International Membership (2 People) $136.00
Lifetime International Membership $1,000.00

(Add $10.00 to memberships in Canada and $25.00 to memberships outside of the U.S. and Canada to cover additional postage costs.)

Fill in appropriate membership rate on Line 8 on reverse side of this form.

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1998 TASH Conference - Creating Futures Together
December 2-5

Registration Rates 1998 Conference	**Current or Joining International Member**	**Non-Member**	**Please Enter Applicable Cost**
General	$199	$305	
Student/Paraprofessional/Parent (Professional)	$135	$229	
Self Advocate/Parent (non-professional)	$ 49	$ 79	
One Day Only Thurs Fri Sat	$ 99	$129	

1. Cost of Conference Registration from above .... 1. ______
2. Subtract Discount if applicable. **(Note: Only one discount can be applied.)**
   a. Subtract $20 for full conference Earlybird Registrations (must be faxed or postmarked by September 18th) .... 2a. ______
   b. Subtract $20 per registration for groups of 5 or more registering for the full conference (all registrations must be mailed in the same envelope) .... 2b. ______
   c. Subtract $50 per full conference registration for a regular education teacher registering with a special education teacher, a paraprofessional, or related services personnel; or for any support staff person registering with a self-advocate (must be mailed in the same envelope). Indicate name of person with whom you are registering:
   ______ .... 2c. ______
3. Add $40 late fee if you are registering after November 13th. After November 13th, all registrations will be on-site .... 3. ______

TOTAL Conference Registration Fee .... 4 ______

TASH Techs:

TASH Members	$65	1st Choice TASH Tech # ______
Non-Members	$80	2nd Choice TASH Tech # ______
Self-Advocate/Parent	$40	

Note: There is no charge for the Chapter Leadership TASH Tech.

5. Add Cost of TASH Tech (full day pre-conference workshops; see descriptions, page 7) .... 5. ______
6. Add $85 to attend the Special Pre-Conference Symposium on Dual Diagnosis .... 6. ______
7. TOURS
   a. Add $42.00 for the Grapes & Hops Tour (see description on page 3) .... 7a. ______
   b. Add $28 for the Seattle City Tour (see description on page 3) .... 7b. ______
8. Add TASH Membership Dues if you are joining TASH International or renewing with this application (see rates on front page of this form) .... 8 ______
9. Add $15 to also join your TASH Chapter (only applicable if you are joining or renewing membership for TASH International now) .... 9. ______
10. Yes, I will add $5 to support a self-advocate to attend the conference .... 10 ______

TOTAL Enclosed (Lines 4-10) .... ______

Payment Terms

Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from cancellations received before November 13, 1998, and added to purchase orders not paid within 30 days after the conference. No refunds will be given for cancellations after November 13, 1998. A $15.00 fee for returned checks or unauthorized charges will be assessed.

Check enclosed Purchase Order/State Voucher No. ______

Visa Mastercard Discover Card Number ______ Exp. Date ______

Signature ______

TASH TECH Pre-Conference Seminars

Registration for pre-conference seminars is in addition to conference registration. For costs see registration form on page 6.

T-1 Specific Strategies to Support Friendships and Community Connections between Adults with and without Developmental Disabilities

Angela Novak Amado

Full community participation includes friendships and relationships with a wide variety of people. This workshop presents very specific strategies and practical "how-to" exercises successfully used across the country to promote community belonging, valued social roles, and friendships with community members.

T-2 Navigating the Autism Treatment Maze

Pat Mirenda

This interactive workshop will provide information about various treatment approaches for autism as well as a format for evaluating them, in a practical, non-confrontational format. The session will assist parents and professionals to understand the options available and make informed decisions about their use.

T-3 Abuse and Neglect of Individuals with Disabilities: Information for Practitioners

Wayne Crawford

This session provides an overview of abuse/neglect, examines roles and responsibilities of practitioners in the investigatory process, and explores how practitioners can act collaboratively to protect the interest of individuals with significant disabilities. An interactive format and case studies will be used.

T-4 A Toolkit for Involving People with Disabilities as Project Leaders

Marilyn Bown, Tamera Dalton, Troy Pope, Jess Kenney, LaNae McKenna, Taunya Day, Claire Mantonya, Gerald Glenn, Rich Wilson, Paul Day

The project that is the basis of this workshop is a very successful person-centered planning and training project which partnered people with and without disabilities as team members. This workshop will include video clips, panel discussions, and a practical toolkit that includes everything you need to get started planning your own project.

T-5 Fostering Social Relationships and Building Peer Supports

Marti Snell, Rachel Janney, Kenna Colley

This workshop will present approaches for building peer support and promoting social relationships between students with and without disabilities. We will give opportunities for participants to apply concepts to case students.

T-6 Creating Inclusive Learning Communities: Curriculum, Community Building, and Reflective Practice

Lucille Zeph, Mara Sapon-Shevin, Mary Fisher

This session is designed to address some of the questions that continue to challenge families and educators who are interested in developing general education classrooms where effective educational practices combine with effective community building strategies to create learning communities where all participants are valued and successful learners.

T-7 Strategies for Successful Inclusion in the Core Academic Subjects: Grades 4-12.

Kathy Gee, Kimberly Strain

A general education secondary teacher in the humanities and social sciences field will team with an inclusive schooling specialist to provide a lively workshop utilizing media, real classroom materials, and activities. The focus will be on creative strategies for upper elementary, middle, and high school inclusive classrooms: curricular issues, instructional strategies, adaptations, modifications, and accountability.

T-8 Alternative Assessments: Innovative State Approaches

Jacqueline Farmer Kearns, Dee Spinkston, Martha Toomey, Sarah Kennedy, Harold Kleinert, Mary Pat Farrell, Sue Buchard, Sandra Warren, John Haigh

This session will showcase innovative approaches from Kentucky, Delaware, West Virginia, Maryland, Colorado and North Carolina. Panel representatives will share this information in a full day agenda devoted to implementation issues.

T-9 Creating Creativity

John Irvin

This is an interactive workshop that presents creativity as a holistic skill that can be learned and developed. Creativity is more that just a way of thinking. It is inclusive of how we think, act and speak to one another and to ourselves. It is the skill of allowing oneself the freedom to create. Participants will receive a creativity kit to help facilitate their ongoing creativity in the work and home setting.

T-10 Providing Effective Services for Young Children with Autism: Blending Approaches to Meet Individual Needs

Ilene Schwartz, Susan Sandal, Bonnie McBride, Gusty Lee Boulware, Ann Garfinkle, Stacy Shook

The purpose of this workshop is to provide participants with an overview of strategies that are effective with young children with autism and PDD. An emphasis will be placed on blending the strengths of different disciplines to create programs that are effective and appropriate for young children. Issues that will be addressed include: curricular issues, instructional strategies, the role of peers, and the generalization of behavior change.

T-11 Understanding SSA Disability Benefits: It's Easier Than You Think!

Paul Selby, Connie Ferrell

Fear of losing SSI is a major concern of many individuals. The purpose of this session is to heighten awareness of adult SSA disability programs and to present strategies for advocating for the individual with local SSA personnel.

T-12 Funding Assistive Technology for Young Children

Mary Jane Rapport

This session will provide an overview of federal laws and regulations pertaining to the provision of assistive technology devices and services to young children. Relevant legal discussions and letters from federal agencies clarifying issues will be discussed.

T-13 Creating A Culture of Inquiry: Participatory Action Research Methodology

Gail McGregor, Hyun-Sook Park, Jean Gonsier-Gerdin, Stacy Hoffman, Elizabeth Kozleski, Dick Sagor, Chris Salisbury, Anne Smith, Susan Whaley

In this session, participants will be introduced to participatory action research methodologies that are being used in two federally funded projects that are actively exploring the link between policy, research and practice. In both of these projects, school personnel and other stakeholders are functioning as active partners and/or researchers, focusing their efforts on issues of inclusion and school reform.

T-14 From Networking to Netweaving

Gary Donaldson, Cary Griffin, Stephen Stekas

This workshop focuses on how to transcend organizational boundaries in order to facilitate sustainable membership of persons with significant disability in the fabric of community life. Netweaving is a metaphor for forming new patterns of collaboration and partnerships between diverse segments and sectors of the community. Participants will learn how to leverage existing community resources by using strategies that create and add value for mutual gain.

T-15 Positive Behavioral Support and Its Application to IDEA

Rick Amado, Bobbie Vaughn

This session provides the most current resources and information regarding changes in IDEA directly related to positive behavioral support, followed by a presentation of the positive behavioral support process. The format will be very interactive, and will concentrate on contextual fit, functional assessment, and multicomponent support plans.

T-16 Ethics of Touch

Dave Hingsburger

This workshop is aimed at direct care staff who are required to provide physical assistance in any form to a person with a disability. This interactive workshop will address complex issues including: affectional boundaries between care providers and care recipients; provision of intimate care while maintaining respectful boundaries, avoiding potentially abusive situations or a situation that could be misconstrued as abusive, and establishing an environment that allows people with disbilities to distinguish those who help from those who hurt.

T-17 Including Students with Disabilities as Fully Participating Members of the High School Community

Carol Tashie, Mary Schuh

Why students with disabilities should spend their high school career with all peers and strategies for overcoming obstacles that cause students to spend time away from typical peers will be discussed. What students should be learning in classes, after-school, weekends, and the transition to jobs will be discussed.

TC - TASH Chapter Leadership and Development Day

This free leadership development session is for TASH Chapter Officers, chapter members and people interested in forming or joining a TASH Chapter. An interactive day, which includes lunch for pre-registrants, is planned around formal presentations on building and maintaining community support, networking and building alliances with other organizations, building and strengthening international and chapter relationships, and influencing policymakers. Participants will have opportunities to share chapter accomplishments and discuss other issues of importance to chapters.

Pre-conference Symposium on Dual Diagnosis

Introduction to Dual-Diagnosis: Assessment and Management of Psychiatric/Behavioral Conditions in Persons with Developmental Disabilities

TASH is pleased to announce this symposium, which is jointly sponsored by TASH and the National Association of the Dually Diagnosed.

Presenter: Ann R. Poindexter, who is a licensed physician. She is presently a self-employed health care management consultant for persons with mental retardation and psychopathologic diagnoses. She has practiced, researched, and presented extensively on topics relating to psychiatric diagnosis and treatment of persons with developmental disabilities.

Description: Overall incidence and importance of behavioral/psychiatric problems in individuals with developmental disabilities will be outlined, and a simple diagnostic scheme will be discussed. Common medical conditions, which are easily mistaken for behavioral/psychiatric conditions, will be presented. The most common psychiatric conditions seen in persons with mental retardation will be presented, along with appropriate mnemonics and "clue lists" to facilitate diagnosis.

The fee to attend this workshop is $85.00. Please use the form on pages 5-6 to register.

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Securing Self-Determination: Building the Agenda in Canada

BY MICHAEL BACH

Much has been written and said in recent years of the need to better protect and promote the self-determination of persons with intellectual disabilities. In Canada, a number of initiatives are underway to address the legal, policy, and service delivery structures which have resulted in systematic removal of this basic citizenship right from so many adults with disabilities. It has been over twenty years since the first efforts to establish policies to secure greater self-determination for people with intellectual disabilities. Since that time, this agenda has advanced substantially, even if the obstacles are now appearing that much more complex and formidable.

Exclusion from citizenship and self-determination is rooted in concepts of what it means to be a person worthy of recognition and respect and in the laws which have sought to secure and construct this figure. To advance the agenda for change, we must reach back to question the classical conceptions of "reason" inherited from Plato and others, and entrenched in centuries-old conceptions of state responsibility for those deemed to be on the "other side" of reason. Unless we do so, the agenda for securing greater self-determination will remain theoretically weak and ineffective in policy, programmatic, and practical terms. It will remain limited, as it is now in many settings, to a skills-based conception, rather than a rights-based one. That is, the focus will be on whether people have the skills and capacity to make this or that decision, and on the strategies to teach them to do so, rather than on the structural conditions which have removed their right to exercise self-determination in the first place. As long as self-determination is seen as a skill, as much research and many service evaluation models suggest it should be conceived, then it will be left up to the researchers, psychometrists, and service providers to determine when people reach the threshold of skill to recover their citizenship.

There is no singular event that marks the moment in Canada at which the multitude of personal hopes for greater self-determination, and the personal pain of its denial, reached a collective consciousness and became a public concern. But there are some major milestones along the way. One of the moments that has had enduring effect in creating a public concern and accountability for securing greater self-determination was in the mid-1970s in British Columbia. A group of parents known as the Woodlands Parents Group, named after the institution where their sons and daughters lived, stepped back to analyze why it was that their family members were incarcerated, and what would give them the rights to self-determination. The group had been galvanized, in part, by Gunnar Dybwad's visit to the Woodlands facility in 1976 and his subsequent report to the media about the deplorable conditions for those living there. As the parents met together, remembering and reviewing their stories about why it was that their sons and daughters had been placed in the institution, they came to two conclusions: individuals lacked control over the funding that was being used to keep them in the facility and they lacked the planning support to assist them in purchasing and arranging needed supports in the community.

The Group presented a proposal to the provincial government for "individualized funding" and "service brokerage," tools they proposed would give individuals the power they were lacking. Individualized funding would be allocated to individuals on the basis of their personal goals and plans for support in the community and a service broker accountable to the individual -- and not to the government or community service providers -- would assist the person in arranging needed supports. While the proposal was adopted and funded to a certain extent, the model of individualized funding and service brokerage was never fully adopted in British Columbia. The legacy of the Woodlands Parent Group lies in the conceptual framework for funding and supports that grew out of their fundamental commitment to self-determination. Over twenty years later, policies, programs and demonstration initiatives for individualized funding for disability-related supports are being adopted across the country, and internationally.

At the same time that the parents movement was formulating a framework for individualized funding and service brokerage, the Independent Living Movement, first in California and later in Canada, was reaching the same conclusions about the relationship between funding, control over disability-related supports, and self-determination and inclusion in society. Throughout the late

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1970s and 1980s various "direct-funding" pilot projects for people with physical disabilities were established in provincial jurisdictions in Canada. A body of experience, policy development, and program evaluation demonstrates both the viability of this approach to funding, and its necessity in ensuring that people are able to guide their lives toward the personal and collective aims they choose.

Despite the legacy of a framework to secure individualized funding, the necessary policy and program conditions have not been adequately formulated or adopted on a national scale. Political, legal, service delivery, and policy barriers now restrict wider implementation of individualized funding and independent planning supports. In reviewing some of these barriers and how they have been addressed, additional conditions for securing self-determination become visable and a future agenda for change becomes clearer.

One of the most entrenched barriers to individualized funding and to self-determination more broadly is the legal distinction established in law between the "competent" and "incompetent." Rooted in 14th Century English statutory law, and reflected in various competency-related laws such as guardianship provisions, this legal distinction has been one of the major obstacles to people with intellectual disabilities obtaining control over their funding for disability-related supports. Capacity to enter service contracts and employ support providers is questioned, and often this status is denied solely on the basis of an individual having an intellectual disability. Orders of supervision in institutions, formal guardianship orders, interpretations by Canada's tax department (Revenue Canada), liability and other requirements on physicians and financial institutions to ensure legal capacity to make decisions have all conspired to deny decision-making status. Efforts to overcome these legal barriers have been promoted through work by various groups in Canada to develop a "supported decision-making model," as an alternative to guardianship.

A number of common elements define the model of supported decision-making advanced in legislative proposals, and already enacted in statutory provisions for the "reform" of guardianship law in Canada. First, supported decision-making is based on a set of guiding principles which emphasize the person's right to self-determination and autonomy, the presumption of capacity, and right to decision-making supports to enable equality before and under the law without discrimination on the basis of disability. Second, the model recognizes that a person's will and intent can form the basis of a competent decision-making process which does not remove a person's decision-making rights. Third, the model acknowledges that decision-making assistance is often required by any individual. This could include interpreter assistance, facilitated communication, assistive technologies, or plain language. Legal provisions have been adopted in British Columbia, Manitoba, and the Northwest Territories that legally validate these elements of a supported decision-making model.

Nonetheless, thresholds of legal capacity persist, even if they have been redrawn to include in the category of the legally "competent" those persons that would have otherwise lost their decision-making rights. A more fundamental challenge remains: providing the theoretical and moral foundations for changing the highly individualized notions of self-determination that dominate guardianship, contract law, and public policy. A perspective is needed that connects the exercise of self-determination to community. In his book *Liberalism, Community and Culture*, Canadian philosopher Will Kymlicka refutes the idea that we make and exercise personal decisions that guide our lives outside of a relation to our communities, identities, language, and culture. While he and other philosophers who critique highly individualistic notions of self-determination have not generally extended their perspective to include people with intellectual disabilities, the implications can be drawn.

Challenges that women and people of color made to the notions of personhood and rationality which excluded them from citizenship and democratic participation now have to be taken up by and with people with intellectual disabilities. Otherwise, the appeal to self-determination will remain a hollow one, and a "skills-enhancing" programmatic response will continue to mark the limits of the political understanding of disability, difference, and rights.

We have seen in recent years in Canada the foundations being built in terms of philosophy, law, and individualized approaches to planning and funding to secure decision-making rights. Beyond the need for a continued philosophical and legal analysis to further alter the limiting construct of self-determination, communities, labor unions, and governments are realizing that there are more than philosophical choices to be made.

If individualized planning and funding of disability-related supports are conditions of greater self-determination, then a fundamental restructuring of the funding mechanisms for thousands of community service agencies is required. There are communities in Canada which have begun to move in this direction. In the city of Thunder Bay, Ontario, for example, community service agencies agreed in the early 1990s to shift from a block-funded approach to disability-related services to an individualized funding approach. A new community governance structure was established to steer the transformation. The community board created an autonomous service brokerage agency to assist individuals and families in planning and negotiating

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the individualization of dollars. Over the same period, deinstitutionalization initiatives were mounted in six provincial jurisdictions in Canada, all using individualized funding mechanisms to transfer dollars out of institutions and into the control of individuals and families to purchase needed community supports.

These transitions have not been easy, nor are they fully complete. A number of issues are being raised:

- What is the role of existing community agencies and the status of labor agreements as dollars are individualized?
- How are agencies to individualize their block-funded dollars when many of them are tied up in services delivered to groups rather than individuals?
- How can the control over dollars and decision-making be transferred to individuals and families without over-burdening them with the administration of those dollars and the management of the services they purchase?
- As a framework of rights and contractual status to hire and fire workers is established for individuals and families, what is to become of unionized workers?

Some are now arguing that it is a zero sum game. If individuals with disabilities are to obtain rights, then workers will have to lose them. Such a position separates the relationship between rights and community, and wins rights for some at the expense of community inclusion for all. The claiming of rights is only one of the steps to building community; without a community that recognizes and works towards securing the rights of all of its members, the claims become divisive rather than constructive.•

There are no simple or singular answers to these questions. What has become clear over the course of these initiatives in Canada is that while individualized planning and funding are necessary conditions to secure self-determination, they are not sufficient. Other conditions are needed as well. Legal requirements to construct the "incompetent" of our society continue to hamper the realization of rights and respectful communities. Individuals need well-supported and sustainable support networks to assist them in obtaining this respect in planning, making decisions, and managing their disability-related and other supports. Individuals, families, and their support networks require planning and management supports that are accountable to them, and not to service providers and government funders exclusively. Community development strategies are needed to build inclusive communities for people.

People require more than individualized funding to become full members. The funding can give them access to supports, and the contractual status and resulting recognition that they are full members of society and communities, but until the educational, employment, recreational, housing, and other sectors begin to better fulfill their human rights obligations to include and accommodate people with disabilities, individualized funding will still only be able to buy "placement" in communities.

There are simply not enough disability support dollars in current public sector budgets, even if they are individualized, to buy all the support necessary for inclusion. And even if there were, people would quickly become consumers more than members in their communities.

In addition, new community governance structures are needed to help manage the transition. Structures are needed that are broadly representative, that can address the various interests of people with disabilities, families, service providers, unions, and funders, and that can build a common ground of respect and recognition to keep the process of transition moving. Finally, we have learned in Canada that without more accountability in government for delivering on existing human rights commitments, and without a more enabling policy framework, communities will not have the tools they need to govern funding and development of supports that lead to inclusion.

Michael Bach is Director of Research at The Rocher Institute, Canada's national institute for the study of public policy, disability, and human rights. For further information on the self-determination movement in Canada or the work of The Rocher Institute, contact the author or phone 416-661-9611 or e-mail at mbach@roeher.ca

Also visit The Rocher Institute's website at http://indie.ca/roe

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What Do Marginalized Groups Have in Common?

A STUDY OF MINORITY WOMEN IN ICELAND

BY RANNVEIG TRAUSTADOTTIR, ASSOCIATE PROFESSOR-FACULTY OF SOCIAL SCIENCES, UNIVERSITY OF ICELAND

This article discusses a research project with three groups of minority women in Iceland: women with disabilities, lesbians, and immigrant women. The study, which is still in progress, attempts to understand what experiences these minority women may have in common. It is, in particular, their experiences as women the project focuses on. The goal of the study is to explore how marginalization and minority status due to different social factors—such as disability, gender, race, sexual orientation, ethnicity, and culture—influence people's lives. What common experiences do different groups of marginalized people have? Do other marginalized groups have any experiences in common with people with disabilities? If so, these groups can learn from each other and common experiences can create a basis for joining forces against discrimination and marginalization. Currently, however, most marginalized groups are isolated from one another and seem to know little about each other's experiences of marginalization and even less about each other's political struggle for equality and justice.

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The goal of the study is to explore how marginalization and minority status due to different social factors—such as disability, gender, race, sexual orientation, ethnicity, and culture—influence people's lives. What common experiences do different groups of marginalized people have? Do other marginalized groups have any experiences in common with people with disabilities?

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The Icelandic Cultural Context

Iceland is a small island in the North Atlantic. It is one of the Nordic countries and is unusually homogeneous with regard to race and culture. The settlers came from Norway, mostly between the 8th and 9th century, and the descendants of these settlers are the country's indigenous people. Immigrants from different racial and cultural backgrounds have just recently began moving to Iceland. Due to the country's small and historically homogeneous population—Iceland only has 260,000 inhabitants—immigrants of different racial backgrounds are quite visible. With no history of racial and cultural diversity among its small population, Iceland has been characterized by one people, one language, one culture.

Differences in terms of social class have been smaller than in most other places. Icelandic culture and society tends to celebrate and emphasize sameness, not diversity. The only issues of difference or diversity that have historically been found among the population has been within the Nordic race that has inhabited the country. This diversity, due to social class, gender, ability, age, and sexual orientation, has, however, been minimized in the public discourse and largely hidden. The only difference that has been seriously discussed over the past decades is based on gender — largely due to the women's movement and feminist researchers — which has initiated public discourse on gender issues. Thus, Iceland presents an interesting place for study of minority groups and the current research is one of the first in-depth attempts to understand Iceland as a multicultural society and examine the situation of the country's minority groups.

The Study

Marginalized groups in Icelandic society have not been the focus of

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scholarly endeavor and there is little knowledge available about the social forces that influence their lives. The multiple marginalization of minority women—first as women and second as members of another minority group because of disability, sexual orientation, race or culture—makes them ideal in the study of marginalized groups since their double minority status exaggerates the processes of marginalization. In this study we place specific emphasis on examining traditional women's roles in order to understand what these different groups of minority women have in common as women.

Each of the three groups — women with disabilities, lesbians and immigrant women — are in themselves very diverse. In order to make the study more manageable we have narrowed our focus with two of the groups. Within the group of women with disabilities, we have mostly, but not solely, focused on women with intellectual disabilities. Within the group of immigrant women, we have directed our efforts toward women who have immigrated to Iceland from Asian countries.

The study has been carried out by a team of four researchers. In addition to the author, three graduate students at the University of Iceland have worked on the project from the outset.[1] The study started formally in 1996, but prior to that the research team had conducted smaller studies with two of the minority groups. The work on the study will continue until 2001, at which time the current grant from the Icelandic Research Council will end.

This is a qualitative study and the main method of collecting data has been participant observation. The research team has spent time with individual women or groups of women where they come together in public and private settings and the team has emphasized long-term involvement to gain an in-depth understanding. The involvement of the researchers has lasted from a few weeks up to 2 years. With a small number of the women, however, the ongoing contact has been sustained over a period of more than 3 years. Besides this long-term involvement through participant observation, the research team has conducted in-depth interviews with a number of women from all three groups, some of their family members or friends, and with people who are connected with these groups through their work.

Common experiences can create a basis for joining forces against discrimination and marginalization.

The data is collected separately for each group. Each researcher has "specialized" in one group although most of the researchers have in-depth knowledge of the other groups, as well. In the process of data analysis the research team has attempted to draw out the commonalties and differences among the three groups. First, each researcher analyzes her own data individually, then the team comes together as a group and analyzes the data collectively in order to identify the experiences the three groups of women have in common. Some of the study's preliminary findings follow.

Findings

In the research team's field work, they were struck by the difficulties all three groups of women have had in gaining access to traditional women's spheres and roles. Many of the findings relate to how "womanhood" — that which makes women women — seems to be problematic for all three groups. As a result, the team focused particularly on the women's experiences in this area. Two of the central aspects the researchers identified in this area were womanhood and motherhood. The article concludes by reflecting on, first, what the study can tell us about the common experiences of marginalized groups, and second, what we can learn about mainstream society by studying the lives of marginalized groups.

Womanhood

Gaining the social status of a "woman" is problematic for the women in all three minority groups. Many of the social and cultural dynamics that have to do with access to traditional Icelandic women's spheres and womanhood itself is difficult for these women. This manifests itself in different ways for each group, but the end result is the same: they have difficulties gaining the cultural status of a "woman" or a "normal" Icelandic woman.

Women with intellectual disabilities are usually not regarded as women or defined as "normal" women. One reason is that they are commonly seen as "eternal children" and not as grown-up mature women. The vast majority of the women with intellectual disabilities in the study, all of whom are adult women, tend to be treated in a child-like manner, talked to as children, and so on. Their disability also increases the notion of them as "abnormal" women. They are, perhaps, the group that has the greatest difficulty in gaining access to womanhood and the status of a woman. One

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[1] The three graduate students who have worked on this project are Anna Einarsdottir, Hanna Bjorg Sigurjonsdottir, and Sigurlaug H. Svavarsdottir. The author gratefully acknowledges their important contributions to the study.

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aspect of this is that it is seen as particularly inappropriate for them to express their sexuality in any way.

Lesbians are not seen as "normal" women. Their lifestyle and their sexuality threaten traditional womanhood and challenge the heterosexual order of Icelandic mainstream society. Although gays and lesbians are allowed to marry in Iceland, any expression of sexuality in public is seen as inappropriate. Despite increased legal and civil rights in recent years, lesbians are still viewed by many as abnormal and do not fit the cultural norm of "womanhood." The stereotype of lesbians as masculine or man-like exaggerates the view of them as non-women.

Immigrant women from Asia suffer from a public image in Icelandic society as mail-order brides imported by Icelandic men who cannot deal with strong and independent Icelandic women. This image is negative and contrary to the beliefs of many. Only a very small number of Asian women have come to Iceland for the purpose of marriage. However, this belief has created a view of this group of immigrant women as "loose" women available for sexual favors. In a sense, they are seen as exaggerated women in the sexual sphere. In addition, they do not fit the image of "normal" Icelandic women because they do not conform to the Icelandic cultural code of womanhood.

All three groups have difficulties being recognized as "women," as "normal women," or as "Icelandic women." Although their difficulties in this area express themselves in different ways "womanhood" is clearly problematic for all of them and they are seen as failing short of the socially and culturally acceptable norm in this sphere. It is also problematic for women in all three groups to express their sexuality. If they try to do so, their behavior is seen as inappropriate or a threat.

Motherhood

Motherhood is often seen as the essence of womanhood and the most important aspect of being a woman. It should, therefore, not be surprising that the women in this study have difficulties gaining access to motherhood. We found that all three groups have difficulties in this area and it seems to be related to the view of them as "non-women," "failed," or "defective" women. Below is an overview of how this manifests itself for each group.

Women with intellectual disabilities have the most difficulty in gaining access to this important and central aspect of womanhood. Motherhood, which is seen as the natural goal for "normal" women, is regarded as highly inappropriate for women with intellectual disabilities. A small number of the women with intellectual disabilities in this study have been sterilized to prevent them from having children. One woman who did become pregnant was forced to have an abortion. Some of the women who had children lost custody of them, either because the children were taken away from them and placed in care or because they lost custody to their non-disabled husbands. In its attempt to prevent women with intellectual disabilities from taking on the role of motherhood, Icelandic society has created multiple ways to prevent them from having or raising children.

Lesbians are also seen as "abnormal" women and it is not regarded appropriate for them to become mothers. In Iceland, lesbians are denied access to reproductive technology, thereby limiting their access to motherhood and sending a strong signal about motherhood being inappropriate for them. Some of the lesbians in our study who do have children feel a great deal of pressure on them as mothers due to the fact that many people see them as unfit to raise children. People fear they will pass their "abnormality" on to their offspring or that their children will suffer or become "damaged" from growing up in a lesbian household. Some of the lesbians in our study had been under a direct threat to lose custody of their children because of this. Lesbians are also more likely to lose custody of their children in custody battles than are heterosexual woman.

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Icelandic culture and
society tends to celebrate
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not diversity.

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Asian immigrant women in Iceland do not face as great prejudices in the area of motherhood as do the other two groups. They do, however, have difficulties in their roles as mothers and are suspected of being "defective" or lacking when it comes to raising children. Mostly they are suspected of not being able to raise "proper" future Icelandic citizens because they do not know how to cook Icelandic food and do not know the country's customs, history, or language. Asian immigrant women also have difficulties in custody battles. Most of them have only been in the country for a short time and find the Icelandic language exceedingly difficult to learn. As a result, it takes most of them a long time to become culturally competent. This makes it hard for them to fight

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custody battles. In addition, their perceived cultural incompetence and lack of language skills weighs against them when it is considered who should have custody of the child.

For many women motherhood is seen as natural, as a given, and a central aspect of life. The difficult access to motherhood experienced by all three groups of minority women is an indication of their marginalization and lack of access to "normal" or mainstream life in Icelandic society.

Conclusion

This article is a very brief and simplified account of a complicated long-term study of three groups of minority women in Iceland. However, it does present two important points. The first lesson has to do with the common experiences of marginalized groups, and the second centers around what we can learn about mainstream society by studying its marginalized groups.

First, what lessons can we learn from this study about the common experiences of marginalized groups? The three groups of minority women who participated in this study would seem very different—and they are. They do, however, share being on the margins of society, which creates some common experiences. In this study we have traced how social processes of exclusion create similar experiences and situations for different groups of women and the three groups have much more in common in this regard than the research team initially anticipated. I believe that identifying common social processes of exclusion creates a clearer understanding of the forces that marginalize unwanted groups. Identifying how these processes work across different groups unmasks the larger social and cultural issues, thereby creating a better understanding of the social forces that are beyond the control of the individual, yet influence and shape peoples' lives. This provides an alternative view to the one that points to individual characteristics or "defects" as the cause of social marginalization. This, in turn, gives marginalized groups knowledge that can be used in fighting against discrimination and marginalization.

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. . . social processes of exclusion create similar experiences and situations for different groups. . .[and] identifying common social processes of exclusion creates a clearer understanding of the forces that marginalize unwanted groups. Identifying how these processes work across different groups unmasks the larger social and cultural issues, thereby creating a better understanding of the social forces that seem to be beyond the control of the individual, yet influence and shape peoples' lives.

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Second, what lessons can we learn about mainstream society by studying its marginalized groups? As this study has progressed we have come to think of it as a study of the social construction of gender/woman and the relationship between biological and social "woman." The three groups of minority women who participated in the study are biological women. There is no disagreement on that. They do, however, have great difficulties in being recognised as women in the social and cultural sense. The experiences of the women in this study make it clear that it is not enough to be a biological woman to gain access to "womanhood." Examining which women are denied access to the social and cultural status of a "woman" gives us a unique understanding of how societal forces operate in the social construction of gender and the socially acceptable female. This study of the three marginalized groups of women in Iceland demonstrates that the "normal" Icelandic woman, the one who is accepted in the mainstream of society, is non-disabled, heterosexual, and white.

Dr. Rannveig Traustadottir is Associate Professor in the Faculty of Social Science at the University of Iceland. She received her Ph.D. from Syracuse University. Dr. Traustadottir is currently a Visiting Scholar at the University of California, Institute of Health and Aging in San Francisco. For more information on this study, contact Dr. Traustadottir in care of Timothy Diamond at 415-502-5205 or by e-mail: rannveg@itsa.ucsf.edu

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The experiences of the women in this study make it clear that it is not enough to be a biological woman to gain access to "womanhood." Examining which women are denied access to the social and cultural status of a "woman" gives us a unique understanding of how societal forces operate in the social construction of gender and the socially acceptable female.

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WANTED:
People with Disabilities Involved in International Development

BY SUSAN SYGALL

Having recently returned from a month-long consulting trip to Vietnam and Micronesia, I continue to be impressed by this truth: in order for people with disabilities throughout the world to gain empowerment and human rights, more people with disabilities and our allies need to become involved with the grass roots organizing of people with disabilities throughout the world. As it is not possible to describe my entire trip and all of the amazing experiences I had in a short article, I have chosen to highlight certain aspects of the trip and the impressions which have stayed with me since I have returned home.

I have been to Vietnam twice now and both times I have been deeply moved by the beauty of the countryside; the gentleness and optimism of the people I have met; and the vibrant colors, sounds, foods and streams of bicycles that surround me wherever I am. On this trip, I was part of a delegation sponsored by the President's Committee on the Employment of People with Disabilities. We attended a national conference on disability. Since the conference, **the Vietnamese government and people have begun to develop and implement laws that have many similarities to the Americans with Disabilities Act**. This is an exciting time in Vietnam and the government and the organizations of disabled people are mobilizing to improve the rights of people with disabilities.

Vietnam

Following the conference, I traveled with two colleagues: Linda Phelps, who is a nationally recognized Recreation Specialist, and Pat Wright of the Disability Rights Education Defense Fund, who is known internationally for her expertise in disability policy. We spent the next two days in Hue (pronounced Whey), a beautiful, small city. Our hotel overlooked the Perfume River where small boats and fishing fleets could be seen with their nets gracefully billowing in the water. The local markets were comprised of several blocks of brightly colored kiosks filled with tantalizing merchandise: fruits, vegetables, live chickens, immense baskets filled with over 20 varieties of rice and clothing. Residents and travelers alike can find just about anything one might need in these markets.

Clearly my most impressive memory of Hue is of the people we met who are involved with providing services to people with disabilities. We visited a school for blind children and youth that is headed by a strong disability rights activist who is blind himself. The young children who attend school there are extremely proficient in using their styluses to write. They proudly showed off their talents to us with the utmost enthusiasm. They all receive training in what we would call independent living skills, and can cross streets filled with complex mazes of bicycles, mopeds, and cars (all without traffic lights) using bamboo sticks for mobility canes. Some of the children sleep in a small dormitory since they are from far-away areas and have no local family. Some of the children are orphans, so the people at the school are their family. Though the buildings were small and rustic, the philosophy and spirit behind the program was an example of empowerment at its best.

Later we visited a small business run by adults who are blind. Although the production was in a second story building, they brought all of the workers and equipment to the ground floor where we were since I was unable to negotiate the steep stairs with my wheelchair. Again, the determination and optimism to be independent and productive was overwhelming. During a lively discussion, the leaders and workers expressed surprise and happiness to see people with disabilities from another country interested in what they were doing. They had many visitors from development organizations from other countries, but none of these organizations had ever included people with disabilities. By the time we left, we all felt a sense of solidarity that defies words.

During our stay in Hue, we also visited a regular elementary school which had a class of deaf and hearing impaired students. These students are placed in a special class where they learn skills needed to be included in the regular classroom. **Although the students use informal sign language among themselves, there still is no formal sign language in Vietnam, and the teachers use oral communication.** After six months in the skill-building class, the students are moved to the regular classes. As very few people with disabilities attend regular schools in Vietnam, this is a revolutionary program. We spoke with the principal about bringing in teachers who could teach sign language. He seemed interested in the concept but explained that it might be difficult because of the lack of resources in Hue to pay sign language teachers.

Traveling through the countryside, we visited rural health clinics where families with both disabled and non-disabled children receive services. We

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visited a rehabilitation center where families learn basic physical therapy skills so they can help their child to maintain and develop physical capabilities once they have returned to their villages. We also visited the large hospital and medical school in Hue, met many ambitious medical students and had the opportunity to go on rounds with them.

Although medical resources are scarce, the attitudes and optimism were perhaps the most positive I have seen anywhere in the world. When discussing concepts such as inclusive schools, legislative advocacy, the need for universal accessibility, leadership programs, sports and recreation - the response was always "not yet!" The prevailing message to us from the people we met was, "give us information, share your expertise with us, and we will adapt it to what we need and perhaps even do it better." **The requests we received were not for money, but for knowledge, skills and small equipment, such as mobility canes that fold, tape recorders and sign language training. They were also very interested in an exchange between our two countries, comprised of people with and without disabilities who have the skills and philosophy that can enable people with disabilities to achieve their rights.**

Micronesia

Following our ten day trip to Vietnam, Pat Wright and I went to Micronesia to conduct training workshops on leadership and empowerment for young people and adults with disabilities and parents who have children with disabilities. We visited Saipan, Palau, Guam and Pohnpei. Each jurisdiction is quite different in the language, culture and services provided to people with disabilities.

This was my first time in Micronesia and I was struck by the beauty of the lush tropical jungles and abundance of fresh fruit and was awed by the clear waters and variety of fish - they are more spectacular than anywhere I have seen in the world. In Palau and Pohnpei the culture of the islands are well preserved and there are still traditional feasts and rituals that have remained intact for hundreds of years. In Pohnpei we were privileged enough to attend two feasts hosted by the local chiefs. The meals consisted of crabs, fish, fruit and roasted pigs; all of the food was prepared by over 25 families. The sense of tradition and community is well preserved in Micronesia; as the culture becomes more westernized, you have to wonder how that will affect these traditions.

Some of the jurisdictions, such as Guam and Saipan, are covered by our laws (including the Americans with Disabilities Act). **Throughout my travels, at times I have seen the rights of people with disabilities denied because of a pretense stating, "its not our culture."** However, no matter the culture, the rights of people with disabilities to receive an appropriate education, obtain jobs, have physical access to buildings and communication, be treated with respect, use public transportation, become parents and raise families are human rights and should not be denied. Although much progress has been made in Micronesia, there are still many gaps in services that need to be remedied. Our task, supported by the Western Regional Resource Center of the University of Oregon, was to conduct training for people with disabilities and their parents so they would know their rights under the law, know how to organize to insure they have these rights, and to assist the people with disabilities to start their own consumer movement. To accomplish this task and to assist the parent and youth groups in meeting the goals they had identified as important to them, we met with politicians, senators, chiefs, special education directors and business people.

The people with disabilities in Micronesia were thrilled to see other people with disabilities who were not there to teach, but to share ideas and strategies on how to organize. We had some remarkable discussions with parents. They were able to talk about the dreams they had for their sons and daughters and perhaps expand their notions about what could be possible. Parents felt revitalized in their struggle to organize and do outreach to new parents with similar issues.

Something that was especially exciting was seeing some of the teens with disabilities talk about their feelings related to having a disability. Out of their discussions came the decision to change the word used to describe a person with a disability in their language — which means "sick" — to a word which means "someone who has to face obstacles." There was also talk of organizing sports and recreational activities. Perhaps one of the most important outcomes of the discussions was that they began to form their own groups, electing officers and obtaining by-laws and necessary legal requirements to start their own organizations.

First Consumer Conference

Many of the participants from the workshops attended Guam's first consumer conference in March 1998. And so the start of a consumer-led disability rights movement begins. Just as it has happened throughout the world, it often takes just a few committed individuals with passions, goals and a lot of determination and persistence to begin to change the situation of a class of people. It is a long, hard, and complex road but it starts with a few people and a few targeted goals.

More Activists Needed

In both Micronesia and Vietnam, the absence of people with disabilities involved in international development was evident and I believe this is a huge loss for the disability and international development movements. In Micronesia there were no Peace Corps volunteers involved with people with disabilities. Imagine the impact that a Peace Corps volunteer who is blind, deaf, uses a wheelchair or has some other disability could have in such a position; that person could serve as a role model to others and share information and strategies with people with and without disabilities who are committed to improving lives for people with disabilities. In Vietnam there were many international development organizations, but none that I encountered had any people with disabilities as staff or volunteers. People with disabilities and allies need to be involved in the programs that already exist. **We need to get**

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International Development

Continued from page 16

independent living centers, sports enthusiasts and professionals involved with disability services to be an integral part of programs and services in other countries. We also need to invite people with disabilities from other countries to be a part of our organizations.

Mobility International USA (MIUSA) is striving to do our part by organizing a Youth/Parent Leadership Training this summer in which we will invite our colleagues from Micronesia and Vietnam to join us. We are also planning professional exchanges with Vietnam and hope to continue our relationship with the newly formed consumer groups we met in Micronesia. MIUSA hopes to network with other international development organizations to assist them in incorporating disability issues into all of their programs and to be available to send consultants with and without disabilities who have a variety of expertise when needed. With over 500 million people with disabilities throughout the world, the importance of all of us working together is critical. In our ever increasingly interdependent world, all of us have much to gain: having the friendship and trust of people from around the world, learning about new cultures and ways of life, learning new languages, tasting new foods and experiencing new ways of living our lives. In my opinion, that's the only way to live life.

Susan Sygall is the Co-founder and Executive Director of Mobility International USA (MIUSA) located in Eugene, Oregon. MIUSA promotes international educational exchange, leadership training, and travel opportunities for people with disabilities. She is also co-author of several books and videos which discuss the many options people with disabilities have in international educational exchange.

Ms. Sygall can be reached at the MIUSA office at 503-343-1284 (voice/tdd) or 503-343-6812 (fax).

4th Annual International People First Conference – A Huge Success

BY PRISCILLA NEWTON

Snow-capped mountain ranges stretching as far as the eye or the imagination could see formed the backdrop for the Fourth International People First conference in Anchorage in April. Hosted by People First of Anchorage, there were more than 900 people in attendance from 38 states and 17 countries over the course of the 3-day conference. The degree of planning and coordinating of logistical arrangements needed to bring together such a diverse group of attendees from many far away venues was in itself an impressive accomplishment. This feat was made that much more noteworthy because the conference was organized entirely by people with disabilities.

People First chapters are organized across the U.S. and throughout the world to promote the rights of people with disabilities and to advocate for self-determination. And there was much important work going on around disability-related issues, both at the local and international level, at this year's conference.

Inside the Egan Civic and Convention Center, groups of people networked, exchanged strategies and information, and talked about possible solutions to common problems. Conference attendees had opportunities to share insights and gain perspectives about disability issues in other countries. Panels and workshops on independent living, accessible transportation, employment, augmentative communication, personal assistance services, the criminal justice system, and a variety of other topics were convened. Speakers from locations as different as Oregon is to Bangladesh shared personal triumphs and challenges in their quests to move from segregated living environments into homes of their own in the community.

The conference boasted a renowned list of keynote speakers respected for their many years of work in the disability rights arena including Gunnar Dybwad, Lucy Wong-Hernandez, Akiko Ito and Marcie Roth. There was also a special session headed by U.N. panel members from Latin America, Eastern and Western Europe, Africa and Asia to discuss implementation of the United States Standard Rules (on the equalization of opportunities for people with disabilities) in international countries.

There was some time built into the schedule for fun and relaxation, too. Many of the attendees had never been to Alaska and it proved a real thrill to partake of the magnificent scenery, have an opportunity to view uniquely Alaskan widelife, and share the area's incredible history with those people who call Alaska home.

The conference left its mark on Anchorage. Organizers used the occasion to educate and move businesses toward greater awareness of, and compliance with, the Americans with Disabilities Act. The three conference hotels each invested in modifications to guest rooms to make them more accessible for people with disabilities (the Anchorage Hilton Hotel installed a wheelchair lift on its pool and Jacuzzi).

The next International People First conference is scheduled for 2002. No site has yet been selected.

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Girls and Women with Disabilities: A Global Overview

BY NORA GROCE, PH.D.

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This paper is based on an article from The Journal of Disability Policy Studies (Vol. 8).

Over the past decade, there has been increasing recognition that women and girls with disabilities face discrimination on two fronts. Not only do pejorative social attitudes towards those with disabilities limit their options and opportunities in life, but the second class status of females in most societies further restricts what they are entitled to, even within programs specifically targeted towards those with disabilities. For these reasons, women and girls with disabilities are often said to face double discrimination.

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Health Care & Survival

World-wide, girls and women are at increased risk of becoming disabled, and once disabled, they are likely to live the remainder of their lives sicker, poorer and more socially isolated than either men with disabilities or non-disabled women. These risks even precede birth. Girls born into poverty are at increased risk of being born with a disability, because they are more likely to be born to undernourished mothers, to live and work in more physically dangerous environments, to have less to eat and to receive poorer quality medical care or no medical care it all.

In societies where preference is given to boys, particularly in poorer households, families may be slower to expend limited household income on food and medicine for in ailing daughter than for a son. For example, parents may be tempted to wait for a few days longer to buy expensive antibiotics for a daughter's earache than for a son's, turning a simple ear infection into a permanent hearing loss. A mother with several young children may be less willing to walk to the next village to ensure that a daughter receives a timely polio immunization than would be the case if a son was involved.

Where a daughter already has a disability, such practices may be more pronounced, placing female children with a disability at even greater risk for severe illnesses, developing multiple disabilities or even dying. For example, census data in Nepal indicates that the distribution of individuals with "lower limb" disability is 12% in males, compared to 5.9% in females. As almost all lower limb disabilities in this population are attributable to polio — which affects males and females in equal numbers — the imbalance in gender distribution reflects higher mortality rates in female survivors, not higher prevalence rates of polio in males.

Compounding these factors are risks incurred by specific cultural practices faced by females alone. For example, in many areas of sub-Saharan Africa, female circumcision in girls from 6 to 12 can lead to significant and chronic pelvic disabilities, urinary tract problems and mobility impairments. The operation itself, usually performed by local practitioners with unsterilized equipment, places girls at greatly increased risk for a number of infectious diseases, including HIV/AIDS. This practice can also lead to disabling infections and injuries for both mother and child during childbirth.

A girl or woman with a disability is much less likely to receive adequate rehabilitative care than a man with a disability of the same age and socioeconomic background. In many places where rehabilitation services have been established in the aftermath of a regional or civil war, services are restricted specifically to male veterans even though conflicts and landmines take a particularly high toll on girls and women who gather firewood, draw water and work the fields. Where services exist, facilities are often located in cities and require stays of weeks or months. In societies where it is considered improper for a girl or a woman to travel alone or to live away from the supervision of her male relatives, attendance at such centers or female participation in such programs may be very rare.

Not only are girls at increased risk of becoming disabled, but once a disability has occurred, virtually every other expected social role is significantly altered.

Education

Girls with disabilities are routinely confined to their homes by families who fear public disgrace or physical harm to their daughter should her disability become public knowledge. Education for girls and women with disabilities, even in countries where female education is now accepted as the norm, is strikingly low. Furthermore, the education of a girl with

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Girls and Women with Disabilities

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a disability is often disrupted more frequently and ended at a younger age than is the case for her non-disabled peers. Recent UNESCO studies and studies from the World Blind Union estimate that the world-wide literacy rate for girls and women with disabilities in developing countries hovers near 1%.

One reason why many girls and women with disabilities are rarely educated is because their families or societies do not see a need for their education. There is often little expectation that a girl with a disability will live independently or will marry and establish a household of her own. As one often does not become a full adult in the eyes of the community until marriage, lack of marriage keeps many women with a disability forever in the status of "dependent child." (This does not mean that many girls and women with disabilities do not establish relationships, become sexually active or bear children. It means only that their activity is often not acknowledged by the societies in which they live.)

Employment

Although employment rates for girls and women with disabilities are low (according to the United Nations, perhaps only 25% of women with disabilities are in the workforce), this does not mean that most of these women do not work. Here, again, it means only that this work is often not acknowledged by the communities in which they live. Many girls and women contribute significantly to the economic well being of their households by cooking, cleaning, watching children, assembling piece work that will be taken to market by others, and doing the hundreds of chores that make families, villages and societies run. Their contributions are often overlooked by economic planners, their communities and even their own families. In addition to their contributions to their own households, millions of girls and women with disabilities around the world help support themselves and their families by begging. Millions more, unable to support themselves in any other manner and isolated from family, community and societal support systems available to their non-disabled peers, are forced to turn to prostitution.

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A girl or woman with a disability is much less likely to receive adequate rehabilitative care than a man with a disability of the same age and socio-economic background. In many places where rehabilitation services have been established in the aftermath of a regional or civil war, services are restricted specifically to male veterans even though conflicts and landmines take a particularly high toll on girls and women who gather firewood, draw water and work the fields.

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Abuse

Married or single, girls and women with disabilities are at greater risk for physical, verbal and emotional abuse than non-disabled females in the same households. Although statistics on abuse are notoriously inaccurate, it is now believed that girls and women with disabilities face abuse at least twice as often as their non-disabled peers. Furthermore, there is often a prevailing social perspective that in effect states that a female with a disability should be willing to put up with a greater amount of abuse than a woman without a disability because she is "lucky" to get any man.

Moreover, to truly understand the issues faced by women and girls with disabilities around the world, it is important to recognize the fact that the problems they face are complex. The life of a woman or a girl with a disability will be affected by the social and economic class into which she is born, her marital status or potential marital status, her family's social networks, her level of education and the specific type of disability she may have. A daughter with a disability that comes from a wealthy family may be surrounded by a supportive family and family servants. A daughter of a poor family in the same community with an identical type of disability may find herself a street beggar at an early age.

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Major health, education and development initiatives that target girls and women all too often overlook those who have a disability.

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Conclusion

The future for girls and women with disabilities is still cloudy. Major health, education and development initiatives that target girls and women all too often overlook those who have a disability. Many of the local, national, and international organizations that address disability issues tend to reach men, but spend disappointingly little time or attention on the unique psychological, social, economic and cultural issues that complicate and restrict the lives of girls and women who suffer double discrimination because of disability and gender.

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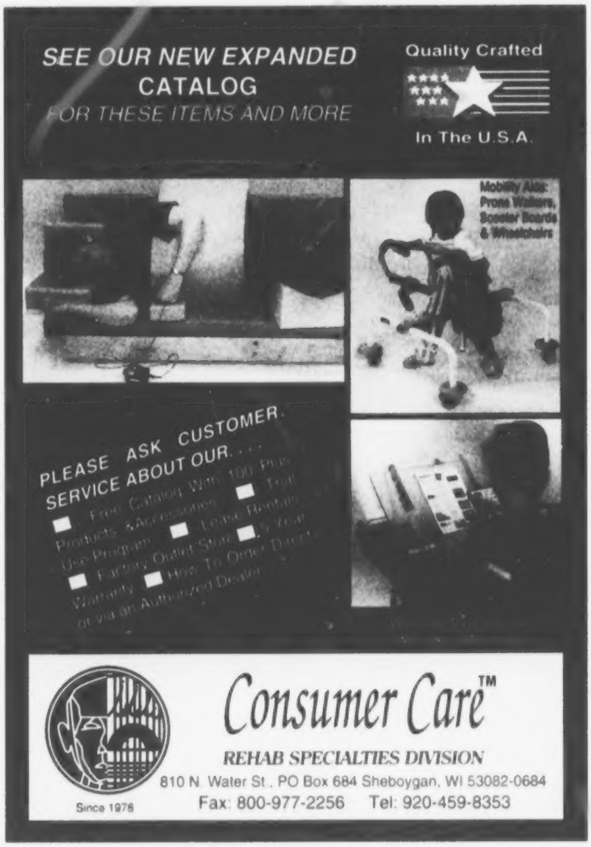
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TASH Multicultural Interest and Action Group

The Multicultural Interest and Action Group worked with the Community Living Group in planning the agenda for The Gathering at the 1997 National TASH Conference in Boston last December. Deciding that our culture is with us at all times, the multicultural interest group took up residency in the Community Living Gathering. Shoeprints of all colors led the way to the Community Living Gathering Place.

The Multicultural I & A Group also held its annual meeting in the "Gathering" Room. Although the Grassroots Consortium was unable to close the Community Living Gathering, a small group of attendees played some "culture games," and talked about cultural and linguistic diversity in a barrier-filled world. In closing, as the group sat in a circle, a small polished stone was passed around the room, with each participant saying what they had gained from the Conference to take back to their community. The keeper of the stone, Joe Wykowski, is charged with returning it to the next "Gathering" for another round of information sharing!

Again, it is the desire of the Multicultural Interest & Action Group to encourage the spread of multicultural issues and topics throughout the 1998 annual conference. It is hoped that this will encourage more people to either find out about their "roots" or learn more about another culture. With this information being provided at the TASH conference, the development of service and advocacy systems that are respectful of cultural and ability differences can be generated throughout the world.

It is still a concern of this Group that diversity begin at the state and local level. The following survey was suggested for each state chapter:

1. What cultures are represented in your area?
2. Do you have cultural diversity in your chapter? If "yes," how do/did you promote diversity?
3. Are you involved in any multicultural committees for other organizations? (CEC, UAP, etc.)
4. Have you developed any culturally relevant materials?
5. Has your chapter supported diversity and inclusion in natural environments?
6. Would you share the names of people in your chapter interested in multicultural issues that would be interested in being on a "list serve?"
7. What can the National TASH Multicultural Group do with state chapters to focus on underserved communities of diversity?

For more information or to participate in the group, contact: Lynda Baumgardner, 307-837-2918 or lbaumg@prairieweb.com

Native American — Communities — A More Inclusive Society?

BY LADONNA FOWLER, THE RURAL INSTITUTE ON DISABILITY, MONTANA

Introduction

I am an enrolled member of the Fort Belknap reservation in northeastern Montana but I presently reside on the Flathead Reservation. My father is an Assiniboine (Nakota) and Santee Sioux (Dakota). My mother was Turtle Mountain Chippewa (Anishinabe). I am the youngest of my brothers and sisters. I still have three sisters and two brothers living (there were eleven of us).

I presently work for the Rural Institute on Disabilities at the University of Montana for the Native American Community Programs which include the American Indian Choices Project and the American Indian Disability Legislation Project. I am the Project Director for both programs.

Family Life

I was born with spina bifida and was not given much hope for survival by the medical profession. Fortunately for me, my parents sought help. My father met a Shriner and found out about the free services for children with disabilities (then known as crippled children). We lived hundreds of miles from the nearest center, but my folks always scraped the money together to get me to my appointments. My early life was spent having corrective surgery for a club foot and major hip operations that were pretty much experimental at the time. I was away from home for months at a time and learned my own survival skills combined with the many things that my mom taught me. My mom and I were very close and she passed on many of her beliefs in order to make me strong in spirit and beliefs.

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Our children have had the benefit of growing up with differences and learning to tolerate all human beings.

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Expectations for me were really no different than for anyone else in the family. I did things in a different way and had to ask for help, but I was very independent. Looking back, I believe that the belief in myself and what I could do was a message that I heard and saw from my family. I had no idea that I was a child with a disability because we saw it more as just health problems that had to be dealt with.

One memory that really stands out was when I was in the seventh grade and had a disagreement with some of the popular girls. I stood up for whatever was the "right thing" and can still hear these girls saying, "...you sure do think a lot of yourself." My response was, "...I know who I am and if that is thinking a lot of myself, then I guess I do." I can remember telling my mom about the conversation and she repeated that I had to know who I was and that I had a purpose for being here. It was my job to find out what that purpose was and not listen to anyone saying things to dissuade me. I think that this was the first time that I realized that others might see me in a different light. Their attitude and statements were a surprise to me at the time.

Adolescence

There was a distinct difference between what I was told (or not told) at Shriners and what I was told at home. At Shriners we were not told anything about sexuality or what to expect as adolescents moving toward adulthood. Yet at home our mother told me and my sisters the facts about our bodies and there was never a lack of expectation that I would not proceed in life as my sisters had (marriage, children, etc.).

I had boyfriends, and was even engaged to be married just before

Continued on page 22

Native American Communities — A More Inclusive Society?

Continued from page 21

graduation. My parents both talked to me about how hard relationships and marriage can be at an early age. They wanted me to have more skills by going to school so that I could take care of myself. I reconsidered the marriage proposal shortly after graduation and proceeded with my education.

Marriage and Parenting

I spent a lot of time experiencing life by going to school, working and occasionally returning home to my family to help take care of my nieces and nephews. But I always wanted to see what was happening off the reservation and would leave again.

Then in 1983 I met my husband, Tracy, while we were both attending school at Oklahoma State Tech in Okmulgee, Oklahoma. Our son was born in 1985 and our daughter was born in 1986. Again, my family was very supportive of our becoming parents. I had difficulties during both of my pregnancies and found myself breaking new ground for my obstetrician in dealing with spina bifida and pregnancy.

I felt a lack of acceptance and had more questions from those individuals outside my family and my community. People could not understand why I would want to "add to my burden" or "make it harder on myself." I was too busy as a new mom to really listen to those type of comments.

My experience with my son was particularly memorable because he was our first born and I had to figure out how to carry him in the wheelchair, to get him around the house utilizing a bassinet, a baby carrier and a stroller.

My most difficult times were when both of my children were toddlers. If you have a mobility issue, then you tend to keep the kids close to you and teach them early on that they can't run away from you. I laughed when I realize that I had developed my mom's same deadly "look" that told my children to stop and stay put!

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I believe in the Native American communities we have a more inclusive society and include people no matter what their abilities. In most Native American languages there is no word for disability.

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Learning Tolerance

Our children have had the benefit of growing up with differences and learning to tolerate all human beings. When other children would ask questions about my wheelchair, my kids were the first to answer rather rudely until we worked on some answers that were based on looking at how "big" the child asking the question was and how much time we had to answer. Sometimes my daughter would point out to other kids that she was able to ride with her mom while they had to walk beside their mom.

My children are now 12 and 10 years old. Kyle just entered the 7th grade and Andrea entered the 5th grade. There is one thing that my children will always be and that is strong disability advocates. They check out accessibility for restaurants, stores, and particularly bathrooms, to see if their Mom can get in the door. They do help out more in assisting me, but I never see it as a burden to my children. They must learn to care for those around them in their community, particularly the elders, and this teaches them more about utilizing an "us" rather than a "me" perspective.

My Spirit Dances

Culturally, we attend powwows in the spring and summer. Our daughter dances and our son is showing more interest in wanting to dance. Even though I cannot join the circle to dance, we still participate by bringing the kids, camping out, and attending the celebrations. I always tell my family that I let my spirit dance and my daughter says that she dances for the people and for me.

I believe that in the Native American communities we have a more inclusive society and include people no matter what their abilities. In most Native American languages there is no word for disability.

There are roles that we have in our families and in our communities. My children know that I work at a national level as a Native American disability advocate and share me and my time, helping others to get services and education around disability. But the bottom line when I get home from travel or commuting is that I have a definite role as the hub of my family.

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Nevada Community Inclusion Conference: Empowerment through Community Inclusion

November 6-7, 1998

This exciting inclusion conference is a collaborative effort among TASH-Southern Nevada, Nevada CEC Chapter, Nevada APSE, the Nevada UAP, the TASH Education Committee and the Community Rehabilitation Program, Region IX at Interwork.

Tentative featured speakers include Dr. Ian Pumpian, Dr. David Mank, Dr. Patricia Rogan, Barbara Buswell, and Dr. Doug Fisher.

We are currently seeking proposals from individuals and groups in Nevada and nationally who have created and/or are utilizing innovative supports for children and adults with disabilities. The proposal should reflect the best of what is happening to connect individuals with their communities to build bridges and supports in such areas as early childhood education, recreation, transition from school to adult life, supported employment, supported living, and strengthening families.

Those who wish to submit a proposal or register for the conference should contact:

Colleen Thoma, Ph.D. • University of Nevada Las Vegas
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The 1998 Executive Board ELECTION

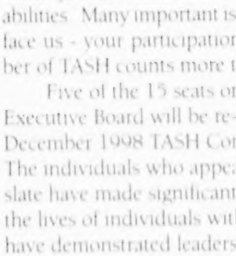
BUILDING TASH LEADERSHIP

Now is the time for you to decide who will help provide critical leadership in TASH's social justice movement for people with disabilities. Many important issues and challenges face us - your participation as a voting member of TASH counts more than ever.

Five of the 15 seats on the TASH Executive Board will be re-seated at the December 1998 TASH Conference in Seattle. The individuals who appear on this year's slate have made significant contributions in the lives of individuals with disabilities and have demonstrated leadership in the disabilities movement.

Your vote is critical. Please use the postage-paid, self-mailing ballot provided on page 29, or clearly write "ballot" on the envelope you use. Ballots must be received at the TASH office by September 30, 1998. Please use ink and vote for five candidates. Voting for more than 5 nominees will invalidate your vote.

THE FOLLOWING ARE THE NOMINEES FOR THE TASH EXECUTIVE BOARD OF DIRECTORS



JACKI L. ANDERSON

Jacki Anderson's ongoing commitment to include individuals with significant disabilities in all aspects of life has been readily evident throughout the three decades she has been in this field. As a classroom teacher, she spent 10 years working in the first integrated California public schools program for students with multiple disabilities, autism and other health impairments. These students, who had historically been served in institutions or segregated schools, taught her the power of teaching in natural environments, the importance of family partnerships in the educational process, and the tremendous need for both advocacy for effective services and educated support personnel.

These important lessons have been the foundation of her efforts as a trainer, researcher, and facilitator of systems change. She has over twenty years' experience conducting inservice training activities around the country and has taught for eighteen years in Special Education teacher training programs at the University of Wisconsin, San Francisco State University, and California State University Hayward, where she has served as coordinator of the masters degree and credential programs in the area of moderate-to-severe disabilities since 1983.

Jacki's areas of specialization include personnel training, inclusion of individuals with significant disabilities, and positive behavior support. She has been awarded funds to pursue all of these interests via research, training, and model demonstration projects and has published the results in textbooks, chapters, and journal articles. She served as Coordinator of the California Research Institute on the Integration of Students with Severe Disabilities(CRI), Director of a series of personnel training projects addressing integration, community intensive instruction and inclusion, and as Training Coordinator for the Rehabilitation, Research and Training Center on Positive Behavioral Support, a six University consortium dedicated to developing and disseminating practical technologies for supporting individuals with behavioral challenges in inclusive school, work and community environments. Over the course of this project, she coordinated the development of a comprehensive inservice training model to establish interagency state level training teams. As a result, a network of 20 State teams is working collaboratively to provide training and technical assistance to assist local communities in building the capacity to provide effective and respectful positive behavioral supports in inclusive settings. She also serves on a variety of national, state, and local committees and advisory boards.

Jacki has been an active member of TASH since 1979 and of CAL-TASH since it was founded in 1982. She is past president of the CAL-TASH board and has been a board member since 1989. Jacki would bring to the board an understanding of and commitment to the relationship between TASH and the chapters. She has a genuine interest in the organization's continued efforts in the areas of advocacy and the dissemination of information via the journal, newsletter and efforts to influence legislation and policy development that support the rights of individuals with significant disabilities to be active and respected members of our society.

DOUG BIKLEN

Doug is the Director of the Facilitated Communication Institute at Syracuse University. For over 27 years he has been actively studying and promoting inclusive education. He has written extensively about community inclusion, disability rights, handicapism, inclusive education, and facilitated communication. During his past eight years, he has focused his energy almost exclusively on facilitated communication, working to ensure its availability to people with disabilities. He is a frequent contributor to JASH, current chair of the Executive Committee, the current conference co-chair, and a lifetime TASH member.

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1998 BOARD ELECTION

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JANIS CHADSEY

Janis Chadsey has been a TASH member for 20 years and has long been concerned with facilitating the communication abilities and social relationships of persons with disabilities. She has worked as a speech and language clinician in the states of Oregon, Washington, and Illinois, and is presently an Associate Professor in the Department of Special Education at the University of Illinois. In her present position, Janis works with colleagues in a program that prepares personnel to teach students with severe disabilities in inclusive classrooms. In addition, Janis is affiliated with the Transition Research Institute where she has conducted research focused on social integration issues involving youths and young adults in high school and employment contexts. In particular, she has taken an ecological perspective toward studying social interactions and relationships recognizing the mutual infuences that environments and people have on one another. Janis has been the recipient of several federal grants, has published numerous articles and chapters, and was recently an Associate Editor of JASH.

Janis is interested in serving on the Executive Board for three reasons. First, she wants to ensure that TASH is viewed as an open and inclusive organization that welcomes a diverse membership to all who are working to improve the lives of persons with severe disabilities. Second, she wants to continue promoting the valued perceptions of people with disabilities at local, state, and federal levels by having people with disabilities set the agenda for this activity. And third, she wants TASH to remain an organization that is not only respected for its work on behalf of individual citizens with disabilities, but is also respected for its work in scholarly and creative endeavors.

JAMES MEADOURS

I am the Self-Advocacy Coordinator for the State of Louisiana, Office for Citizens with Disabilities. I was placed in a sheltered workshop for 6 years and as a young adult lived in a group home with 9 other people for 4 years. I first discovered my interest in self-advocacy when I wanted to exercise my right to vote and sought the assistance of a People First advisor. My involvement in self-advocacy work became statewide in 1989. In 1993 I was elected to a two-year term as President of People First of Oklahoma. I was also elected as the first consumer board member for the Tulsa chapter of the Arc and went on to serve on the Arc US Board of Directors.

In 1995, I was selected to work as a Vista Volunteer for People First of Oklahoma. I also served on the Oklahoma Developmental Disabilities Council. I received a number of awards for my work in Oklahoma and in 1996, Governor Keating proclaimed December 9th as James Meadours Day in honor of my work on behalf of people with disabilities in Oklahoma.

As a result of my national commitment to the self-advocacy movement, I was elected Treasurer and Regional Representative for the national self-advocacy steering committee, Self Advocates Becoming Empowered (SABE). I went on to become the SABE National Co-Chair and have served in this capacity since 1996. I am also presently the Co-Chair of the Young Leaders National Conference.

I have been an active TASH member for several years and am enthusiastic about the opportunity to serve on the TASH Board. I would like to bring my national experience with the self-advocacy movement and my skills developed from serving at the national level to the TASH Board. I think I have what it takes to make a difference. I see people as people first, I see people's abilities, and I am committed to taking the time to listen to and work hard for all of the members of TASH.

JORGE PINEDA

My name is Jorge H. Pineda. I am from Mexico City and have been living in the United States since 1992. I am an accountant by profession and currently work at the National Council on Independent Living in Arlington, Virginia. I have been disabled since birth and have been involved in the Disability Rights Movement since the late 1980s.

In Mexico I worked with other self-advocates to set up an organization to fight for the rights of people with disabilities. In 1991 I was invited to come to the United States to participate in a leadership development program. It was at that time that I really began to learn about all the wonderful work that was being done in this country. One of the results of my trip to the United States is that I met my wife and moved from Mexico to Berkeley, California. I became involved in numerous activities including Fiesta Educativa, an organization to help Latin parents who have children with disabilities. I began to learn about the many problems these people face in this country and have been working with them to help ensure that parents are aware of their rights so that their children can obtain a quality education. Since moving to the D.C. area, I have become involved with and am serving on numerous boards of directors including the Maryland Coalition for Inclusive Education, the Latin American Youth Center, Grupo Esperanza, National Family for the Advancement of Minorities with Disabilities and the D.C. Statewide Independent Living Council.

I am very interested in serving on the TASH Executive Board because I believe I have a lot to offer regarding the needs of Latin people with disabilities and their families. I am bilingual, have experience working with Latin families and my accounting skills will be helpful to the Board. For myself I look forward to the opportunity to be able to learn from the members of TASH in order to continue to help improve the quality of life for Latins with disabilities and their families.

LINDA RAMMLER

I have been serving *ex officio* on the TASH Board of Directors since 1995 and would like to be a voting member of the Board because of the important issues faced by TASH today.

One of the best ways of telling you a little more about myself is to quote the vision and values statement of the consulting firm I co-direct.

"Rammler & Wood, Consultants, LLC is committed to person-centered and family-centered supports. We pride ourselves on achieving these through innovative approaches. We believe that *all* human beings have natural gifts on which to build. We believe that *all* human beings also have common needs for physical well-being, safety, belonging, feeling good about

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1998 BOARD ELECTION

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themselves, and success in their personal aspirations. We believe in self-determination by the individual and, where appropriate, his/her family. We believe in reliance on natural circles of support to the greatest extent possible in assisting the individual to plan and access 'whatever it takes' to achieve his or her desired quality of life. Our vision is that every human being's needs are met satisfactorily and that each individual achieves a lifestyle that is meaningful and fulfilling within a community that celebrates human diversity."

I do a lot of things professionally (such as teaching, consulting, testifying) and personally (in my adult relationships and in parenting my four kids) to try to make this statement come true. I like to think I have boundless energy and, as age tempers that a bit, boundless creativity in suggesting how others (like TASH staff) can direct their energies!

My commitment to TASH has been long-standing — I've been a member since 1982, I've presented at regional and national conferences since 1987, and I've been on the New England Chapter Board since 1990. I continue to advocate for strong Chapter input and I've represented TASH and SAFE in public testimony and other activities. Everything worthwhile that I know about disability activism was taught to me by others who were TASH members. In return, I want to be involved in making TASH accessible and available to everyone else. I want TASH to grow in membership and excitement, to be financially viable, to have its integrity to remain intact, and to grow in name recognition and respect. I would like the opportunity to represent the TASH constituency on the Board formally so that these outcomes can be realized. Thank you!

PATRICK SCHWARZ

Ever since being a child with the "so-called" challenges of being interested in many things at once and displaying boundless energy, Patrick Schwarz has personally known and experienced prejudice, loss of rights and individuals who call themselves professionals that do not put people first. Through self-advocacy, coping mechanisms, belief and positive power, it is Patrick's mission in life to ensure that a dignified lifestyle, with all the freedoms, rights, privileges and fun is afforded to individuals who are most as risk of having it taken away or having none at all in the first place.

Patrick received his teaching degrees under Lou Brown and Anne Donnellan at the University of Wisconsin, Madison. He continued to work with Lou Brown for both his Master's and Doctoral Degrees. "Lou taught me major lessons about upholding quality of life with a passion that you cannot find anywhere else!"

Currently, Patrick accomplishes his mission in life in four ways. First, Patrick is a Professor and Chair of Special Education at National Louis University, Chicago, Illinois. "We are critically promoting and teaching skills each and every educator needs: supporting ALL diverse learners from womb to tomb, promoting collaborative relationships, creating curricular/life adaptations and implementing assistive technology." He also chairs a monthly program area forum which brings together individuals from Early Intervention, Elementary Education, Technology, Middle Level Education, Educational Psychology and Foundations & Research to coordinate teacher training with Special Education. "Yes, we are becoming inclusive at the University level!" "This type of service delivery will reflect a new era for University educators."

Second, Patrick is Director of UCP/Infinitec/Empowerabilty Human Service Agency in Oak Park, Illinois. "This position is all about making connections for people... into their neighborhoods, community, workplaces and society" (adult inclusion)! "There are countless gifts all individuals with challenges offer everyone and doors have to be built and opened."

Third, Patrick owns his own educational consulting business, Creative Culture Consulting, Inc. "I love to be out in the world where it all happens and consulting lets one share in many lives and stories, and hopefully make a difference." He has presented and consulted for ASCD, AIMS, TASH, ICASE, etc., significantly valuing his work with general education organizations. "The meeting of the minds must evolve and become strengthened." This year Patrick also represented the United States for a Pan American Conference in Argentina. "A group of phenomenal leaders in Argentina are working very hard to provide inclusive education, transition services, and supported employment to individuals with significant challenges." Patrick testified before the United States House of Representatives on the reauthorization of IDEA. He also was an expert witness for the Hartmann case in Virginia federal court, as well as several others.

Fourth, Patrick is also currently on the Illinois TASH's Governing Board and has enjoyed the sheer dedication and energy of the constituency. "We are definitely kindred spirits in TASH; these people are family." "It is a supreme honor to be nominated for the International TASH Executive Board!" "TASH means three things to me: people, innovation and quality."

DAVID SHAW

I have practiced law in Hartford, Connecticut for twenty-five years. My practice includes cases involving civil rights of persons with disabilities, special education and malpractice cases. I have concentrated my law practice on issues affecting persons with disabilities for twenty-three years. My first case involving disability-related issues, filed in 1976, compelled the State of Connecticut to purchase exclusively wheelchair-accessible standard size buses.

Some of my other better-known cases include *C.A.R.C. v. Thorne*— a case that resulted in the closure of Mansfield Training School and community placement of its 1,200 residents; *Messier v. Southbury Training* School—a case that seeks decent living conditions and community placement for the 750 residents of Southbury Training School; *ARC/Connecticut v. Tirozzi*—a case that seeks regular classroom placements for the 3,000 children of Connecticut who have a label of mental retardation; and *Brain Injury Association of Connecticut v. Solnit*—a case that seeks decent conditions and community placement for persons with brain injuries currently living in state psychiatric hospitals.

I have also successfully resolved approximately sixty cases that have sought full-time regular classroom placement for children with significant disabilities, and am currently pursuing a case in federal court which challenges Connecticut's refusal to recognize facilitated communication in connection with the development or implementation of a vocational rehabilitation plan.

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1998 BOARD ELECTION

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JACQUE THOUSAND

It is the greatest honor to be nominated for the TASH Executive Board. TASH being one of the most progressive disability rights organizations in North America and one with which I am proud to have been affiliated since its early years.

Since the early 1980s, I have been actively involved with advocacy efforts to instill and install the ethic and practice of full citizenship of children and youth at disadvantage or risk because of perceived disabilities and other conditions. As Coordinator of the Vermont Homecoming project from 1983-1986, I witnessed educators' and community members' beliefs and practices tranform from disbelief that children with significant disabilities should or could be educated in their local home school classrooms to genuine valuing, welcoming, advocacy, support, and successful accommodation of the educational and social needs of every student involved in the project. These early efforts led to statewide changes in educational practice which have served as a model for other states to effect change toward inclusive education from the inside out and the top down.

It was my involvement in the Homecoming Project—what now is referred to as the 'inclusion movement'—that solidified my human rights values and reinforced the importance of being an active member and officer in local and state advocacy organizations (e.g., Vermont Citizen Advocacy, Vermont CEC, Vermont ARC). This service interest quickly expanded to national and international arenas and led to long-term advocacy relationships with Honduras and the Slovak Czech Republics. Since 1991, I have worked with the Honduran Pedagogical University, Ministry of Education, and key human services agencies to develop teacher preparation curriculum which enables the inclusion of students with disabilities in the country's very poor yet public schools. With the advent of the 'Velvet Revolution' in Czechoslovakia in 1989, a similar partnership developed with Charles University in Prague, Czech Republic, resulting in the first Eastern Europe Human Rights Conference being held at Charles University this past September.

I have tried to make a contribution to the field through my writings. Because of my good fortune to live in Vermont, a state so pivotal to the "inclusion revolution," I have had the opportunity to write about some of the "best practices" that have emerged to support inclusive education in journal articles, chapters, and books. At this time, Richard Villa and I are updating *Restructuring for Caring and Effective Education: An Administrative Guide to Creating Heterogeneous Schools*, a book which will bring to the field some of the latest thinking of the family and professional leaders in inclusive education and self-determination in the U.S., Canada, and Norway.

I have been a teacher educator since 1981. At the University of Vermont, I coordinated an early childhood special education teacher preparation program and (following the Homecoming Project) one of the first 'Inclusion Facilitator' graduate programs (1986-1996) in this country. With my move in 1996, to California State University San Marcos, I now coordinate an exciting teacher credential program which dually endorses graduates as general and special educators and, thus, enables them to advocate for and support students with disabilities as either classroom teachers or special educators. As a new Californian, I continue my commitment to community development by working with leadership and staff of local schools to restructure 'Special Day Class' programs and move the teachers and students in these classes into the mainstream. I also am an new member of the Advisory Board of the California Confederation on Inclusive Education, a confederation which links public schools, universities, organizations, state department of education personnel, advocacy groups, and legislators in efforts to promote inclusive education for children with disabilities.

Finally, my interest in supporting children of diverse characteristics led me to adopt a 15-year-old Cambodian refugee 16 years ago. When my son, Chang, came to live with my family, he had no English and virtually no schooling, as he had lived in concentration and refugee camps since nine years of age. During his four years of high school in the U.S., our family became actively involved in ensuring that Chang was educated in general education rather than alternative programs. We experienced the "family perspective" of being the squeaky wheel for inclusion. Today, as a grandmother of three Kahmer-speaking children, my family continues to closely watch and celebrate the language emersion and public schooling they enjoy.

I have presented at annual TASH conferences, written for the JASH journal, reviewed conference proposals, and now hope to serve TASH in a way which will allow my experiences to assist the Executive Board and the entire TASH community to promote the perspectives of individuals with disabilities in policy, legislation, and other advocacy avenues.

DEBORAH TWEIT-HULL

Currently, Deborah serves as a Co-Director of the California Statewide Systems Change Project on Inclusive Education. She has worked closely with families, teachers, students, and administrators in the development of inclusive schools and practices at the school, district and state levels. In the area of teacher preparation, Deborah has also coordinated the Intern Teacher Program, a personnel preparation grant that was a collaborative effort between the San Diego City Schools and San Diego State University and teaches teacher preparation courses in the Department of Special Education at SDSU.

"Inclusion should not end when a student graduates from the public school system" she states. Active in creating inclusive options for adults with disabilities as well, Deborah (along with Mary Ellen Sousa) is the co-creator and Co-Director of Creative Support Alternatives, an agency that provides supported living and community employment services to adults with disabilities in San Diego. "Creating and establishing services that are not only responsive to but actually directed by individuals with disabilities is paramount." Self-determination and control are the focus of a Robert Wood Johnson "Indpendent Choices" grant aimed at the development of consumer co-operatives for personal assistance services in California. Deborah is the local facilitator for that effort in San Diego.

"I would be honored to work with the TASH membership to expand the diversity of its membership, enhance its visibility, and establish alliances with groups and organizations that share TASH's commitment to the values of inclusion, self-determination and social justice."

TASH 1998 Election of Five (5)

EXECUTIVE BOARD MEMBERS

Term of Office: 1998-2001

— OFFICIAL BALLOT —

There are five positions for members of the TASH Executive Board to be filled this year. Positions will be filled via ballot by dues-paying TASH members (one each) in accordance with the Association's By-Laws. The Executive Board member-elects will begin their terms at the Annual Board Meeting held in conjunction with the 1998 TASH Conference, December 2-5 in Seattle, Washington.

Ballot Instructions:

You should vote for a total of FIVE nominees. Ballots containing more than five votes are invalid. Please mark your ballot in ink.

Jacki Anderson
Doug Biklen
Janis Chadsey
James Meadours
Jorge Pineda
Linda Rammler
Patrick Schwarz
David Shaw
Jacque Thousand
Deborah Tweit-Hull

For information about the candidates, please refer to pages 25-28 of this issue of the TASH *Newsletter*.

Mailing Instructions:

Ballots can be returned using this postage-free mailer, or originals of the ballot can be sent in an envelope. If you elect to use an envelope, please be sure the word BALLOT is printed on the front. If you use an envelope, please do not place anything other than your ballot inside; your envelope will not be opened until the counting of the ballots.

VERY IMPORTANT:

ONLY AN ORIGINAL BALLOT WILL BE CONSIDERED VALID.
PHOTO COPIES OR FAXES WILL NOT BE ACCEPTED.

Ballots must be received at the TASH Central Office by
SEPTEMBER 30, 1998

Mail your completed ballot to:

TASH, 29 W. Susquehanna Avenue, Suite 210
Baltimore, Maryland 21204
Attn: Ballot

191

1998 TASH Executive Board Election BALLOT Due in Baltimore on September 30, 1998!

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The Serena Merck Memorial Award

for Innovation and Dedication in Practice

Purpose of the Award The Serena Merck Memorial Award is given annually to an exceptional individual who has demonstrated long-term, selfless dedication and compassion in the care or service to children who have retardation and significant mental health problems. Mrs. Merck recognized the critical importance of what quality day-to-day care provided by committed individuals can make to children with cognitive and behavioral disabilities. The John Merck Fund has established this major, national award to honor her long-standing commitment to this field, and to call attention to the invaluable role caring individuals play in it.

Criteria for Selection of the Awardee Prospective awardees should meet one of the following categories: (1) Provides, as an employee or volunteer, services for children who have mental retardation and significant mental health problems. (2) Demonstrates long-standing commitment and innovative care of this population which has positively affected their quality of life and/or life opportunities.

Submission Guidelines Organizational entities may nominate prospective awardees. One nomination per organization is permitted, although multi-service organizations may submit one nomination from more than one service unit. No self-nominations are acceptable. Only organizations serving children with mental retardation and significant mental health problems are eligible to nominate an individual. A 500-word summary of the reason the candidate is nominated, length of service in the field, and a description of the person's impact on children with mental retardation and significant mental health problems is required. At least two, but no more than five, accompanying letters of reference from individuals well qualified to evaluate the candidate's suitability for the award should be provided.

Nominations should be mailed before September 30, 1998, to:
Mr. Francis Hatch, The John Merck Fund, 11 Beacon Street, Suite 1230, Boston, MA 02108

Award A $5,000 cash award and plaque will be presented to the awardee at the 15th Annual National Association for the Dually Diagnosed (NADD) Conference held November 4–7, 1998, in Albuquerque, NM. The awardee's travel expenses to the conference will also be covered.

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The Independent Living Movement In Latin America

THE BRAZILIAN EXPERIENCE

BY ROSANGELA BERMAN-BIELER

Rosangela Berman-Bieler is a Brazilian journalist, publisher and disability rights advocate. Founder of the Independent Living Movement in Brazil, she is also a founding member and former president of ONEDEF (the Brazilian Organization of Persons with Physical Disabilities), and CVIRJ (the Center for Independent Living of Rio de Janeiro), where she currently serves as Honorary President. Ms. Berman-Bieler was formerly Rehabilitation International Deputy Vice President for Latin America, and is editor of several newsmagazines on disability issues.

Berman-Bieler has served as an expert to the United Nations on disability issues from the Latin American perspective. She was a member of Disabled People International's (DPI) Independent Living Committee and served on DPI's Latin American Regional Committee.

Currently living in Washington, D.C., Berman-Bieler recently served as the Event Coordinator of the International Leadership Forum for Women with Disabilities, held in Bethesda, Maryland. Berman-Bieler operates her own business, Third Millennium Events, through which she produces and edits publications and provides disability-related consulting services. One of her current responsibilities is the newsletter, "One-In-Ten," a collaborative effort between Rehabilitation International and UNICEF on childhood disabilities.

Berman-Bieler has been a quadriplegic since an automobile accident in 1976 and uses a wheelchair.

History of the Disability Rights Movement in Brazil

Until the mid-1970s, the disability issue in Brazil was a subject restricted to people considered specialists in the field. People with disabilities questioned the paternalistic, charitable and guardianship relations. Up until that time institutionalization was the most popular and sought after solution.

With its huge geographic dimensions and serious socio-economic problems, the fifteen million Brazilian citizens with disabilities realized that they could not rely solely on professionals, or count on a change in government attitude. They were also aware that they could not reasonably expect the general population to place issues of disability among immediate social priorities.

The international wave of the self-help movements and the re-organization of Brazilian society at the end of a twenty-year period of military rule sparked the minds of leaders with disabilities who decided to mobilize their fellows to change the then prevailing mentality on disability issues.

During the late 1970s, people with disabilities began to organize themselves into political pressure groups. They were fully aware that if they were to succeed in reversing the situation of abandonment or institutionalization practiced on them throughout history, it would be as a result of their own efforts. The struggle for their rights, for equal opportunities without privileges or paternalism, started in the 1980s, in Brazil as well as in the rest of Latin America, which was recovering from similar periods of authoritarianism.

In 1979, motivated by the appointment of 1981 as the International Year for People with Disabilities (IYPD), organized groups run by people with disabilities came together to discuss the matter. As a result, in 1980, Brazil hosted the first National Meeting of Entities of People with Disabilities. Nearly one thousand participants attended, among them representatives for people who are blind, deaf, physically disabled and those with Hansen's disease (leprosy).

Guidelines for action and the formation of a National Coalition were established in an attempt to encompass all areas of disability. Moreover, a new policy was defined for the year following the IYDP. This policy consisted of representation by people with disabilities themselves and no longer by the self-appointed "specialists."

This new political stance was so strong that it provoked a revolution in the field of disability, generating considerable animosity between the entities then defined as "of" and those defined as "for" people with disabilities. The question of representation reflected not only on social aid institutions, but also on the groups of people with disabilities disputing representation for each area and equal rights in the National Coalition.

During the next three years representation was exhaustively discussed in meetings held throughout Brazil. It was

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INDEPENDENT LIVING

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then agreed that national entities for each area of disability should be created and that these would convene in a Brazilian Council with equal representation.

1984 was a crucial year for structuring the organization. A series of entities were founded: Brazilian Federation of Entities of the Blind (FEBEC); National Organization of Entities of People with Disability (ONEDEF); National Federation of Education and Integration of the Deaf (FENESIS); and the Reintegration Action Group of People with Hansen's Disease (MORHAN). Additionally, a Brazilian Council of Entities of People with Disability was founded in December of that year to aggregate the four entities.

This entire organizational structure was solely devised and managed by persons with disabilities under the motto "Full Participation and Equality," launching a self-help action plan in Brazil for a group which until then had been tutored by the State and charity institutions.

An interesting change with respect to the domination of this field occurred under the new approach. The Rehabilitation Centers and Special Education schools, which until the advent of the IYPD spoke for disabled people, lost a great deal of their representation. This change was especially delicate for entities of the mentally ill, since many were represented by parents and all of them were classified as "for," hence they were initially excluded from the group.

New associations "of" people with disabilities sprouted all over the country, gaining respect from the community. In spite of this, rivalry between different areas of disability continued. The Brazilian Council tried to survive for a couple of years but succumbed to the lack of interest of associated entities. The new way became "each group on its own."

During the 1980s, the self-help movement surpassed national borders and ONEDEF represented Brazil at Disabled Peoples International, by way of its Latin American Council. People with visual disabilities became affiliated with the World Blind Union (WBU) and with the Latin American Blind Union (LABU). Similarly, people with hearing disabilities, through FENESIS, are now part of the World Federation of the Deaf, expanding their political influence and improving their leadership.

A change in attitude with relation to people with disabilities was the result of work undertaken by these leaderships during the '80s. Paternalism gave way to equal opportunities. Full citizenship replaced guardianship.

Strong pressure from disability advocates and the United Nations, through the UN International Year (1981) and later, the UN Decade of People with Disabilities (1983-92), prompted governments to create offices to coordinate inter-ministerial policies covering disability. Gradually, society as a whole began to address all issues related to disability more directly.

Political parties committed to the cause began to emerge, many of which counted among their founding members advocates with disabilities and later candidates who are today serving as members of Congress, Counselors or Mayors of their cities.

A recent Federal Law in Brazil moved the disability cause forward, and the media began giving significant visibility to the issue. Based on an "active participation and equality" philosophy, technicians and professionals began to modernize their charity/welfare attitude.

Nevertheless, essential changes in the very foundations of society are crucial to change the current reality of people with disabilities in Brazil. A real process of social transformation that would positively affect all other disadvantaged groups of the population is needed as well.

To become competitive and reintegrated into the economic mainstream, people with disabilities have to exercise the values of independent living as well as their constitutional rights. They must make decisions about their own lives. The process begins with the rehabilitation process. This is achieved through information, education and activities related to their participation in an inclusive social life.

In order to enable people with disabilities to make their own social contribution, they must gain access to society by leading a full, participatory, and independent life. The best way to accomplish this is through information and empowerment.

Rights Through Legislation in Brazil

As a consequence of the growing self-help movement and its demands, the government began to structure itself in order to assist people with disabilities. In 1987, then President Sarney issued a decree creating the National Coordination for Integration of People with Disability (CORDE), which was formally recognized by Congress in October 1989.

The law assigns the government the task of defending the interests of people with disabilities through the creation of CORDE, and also defines prejudice against people with disability as a crime. Brazil's new Constitution, revised in 1988, has in all of its chapters positive

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INDEPENDENT LIVING

Continued from page 33

The concept of independent living in Brazil is now beginning to be understood. For many people with disabilities it means autonomy to deal with one's own life, and to contribute to the improvement of society.

pieces of legislation — calling for improved transportation systems (to include easy access) and an enlarged job market for people with disabilities — most of which has yet to be totally implemented.

People with disability have their working rights guaranteed by the Constitution, which sets aside a number of positions in the civil service and prohibits discrimination in recruiting criteria or wages. Regarding equal rights in education, the State must provide adequate installations for education, preferably in the public system.

Access to public services are addressed by the elimination of architectural barriers, regulation of building codes and the adaptation of public areas in addition to the manufacturing of public transportation vehicles capable of accommodating the needs of people with disabilities.

The above represents an overview of specific chapters in the law which, supplemented by other articles in the Constitution, prohibit prejudice and guarantee all citizens' rights while promoting the integration of all Brazilians. Unfortunately, in reality in most Latin American countries the institutions are weak, and the system tends to be corrupt and slow with respect to accomplishing law and justice. It is the reason why citizenship and civil rights are distant concepts to the majority of the population. Even with many legal measures related to disability now found in national, state and city laws, there is still only a small portion of people with disabilities who have access to these benefits.

How the Independent Living Movement Started in Brazil

After a period of intense activity and enthusiasm experienced by advocates with disabilities during the first half of the UN Decade for People with Disabilities, in 1987-88 the disability movement began to decline in many parts of the world due to a lack of new leadership and new challenges.

In August 1988, some Brazilian leaders with disabilities, looking for new approaches for the movement, had their first contact with an Independent Living Center in the USA. They compiled a vast amount of information, and adapted its concepts and services to the Brazilian reality. Four months later, the project was completed: The Centro de Vida Independente do Rio de Janeiro (CVIRJ) had been established. This private, non-profit cross-disability organization — totally managed by advocates with disabilities — was founded on December 14, 1988 in Rio, Brazil.

Prior to its creation, CVIRJ's team of advocates with disabilities and technicians had been working together for almost 20 years to attain the social emancipation of people with disabilities through proactive political demand for their rights and through the support work carried out by these self-advocates and their families.

The lack of available time to perform "mere" volunteer work, the need to establish professional status in this field, and the lack of financial resources, among other difficulties, gave the impulse to the creation of the first Center for Independent Living in Brazil and Latin America. Based on the experiences acquired during many years of volunteer work throughout the civil rights movement, it was of key importance to develop a methodology to organize services that could enhance the quality of life — as well as an awareness of both people with disabilities and Latin American society as a whole — in an orderly, objective and professional way.

Which Independent Living Movement Are We Talking About?

"Are there differences between the disability rights movement and the independent living movement in Brazilian and Latin American Cultures?" There are no conceptual differences but, rather, strategic ones. Clearly the disability rights movement, based mostly on volunteer advocacy work, created the basis and social environment for the independent living movement.

The difference between one and the other is that the disability rights movement has never delivered any direct or indirect services to individuals with disabilities. The disability rights movement's strategies were geared to generate public awareness regarding the existence of a significant segment of society that had thus far been largely ignored.

Additionally, the movement proposed the creation of laws aimed at defending the civil rights of its constituents, all while establishing political influence to ensure that their demands were heard.

Advocacy leaders focused their efforts at the entire segment of people with disabilities, never on an individual basis. As a result, they were not practicing independent living or realizing what could be done to improve their quality of life.

Prior to the Independent Living Movement, concepts and services such as, peer counseling; personal assistance; personal autonomy; people with disabilities providing services to their peers and to the community; centers for

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INDEPENDENT LIVING

Continued from page 34

independent living staffed with people with disabilities; leadership training; and professional training programs were non-existent among the local or national organizations.

Consequently, concepts of independent living created a new mentality, dealing directly with the individuals with disabilities:

- "You should be in control of your own life."
- "You should be capable of making decisions and choices about your life."
- "Independence does not mean that you have to do everything by yourself."
- "You should have the right to decide the type of assistance needed for your daily life activities and how to use your time for your own satisfaction."
- "As a disabled person, you should apply your experiences to counsel peers in similar situations as your own."

These concepts generated the line of services current provided by the Centers for Independent Living (CIL) in Brazil. They constitute the "new face" of the disability rights movement, not only based on volunteer advocacy, but also in the empowerment of each individual with a disability.

Conclusion

In Brazil, an evolution of the traditional disability rights movement brought into existence the independent living movement. Initially based solely on advocacy, it progressed to the point where people with disabilities began to learn how to take charge of their own lives. Later, this newly acquired knowledge was applied towards improving the quality of life of their peers.

The disability rights movement grew quickly, having as its basis the leadership of a few advocates in addition to support from social and political elements of society from around the world. Self-motivated and working in their spare time, these leaders had little opportunity to develop strategies concerning new concepts or a new philosophy. Training was non-existent and improvements in their personal empowerment was limited. Additionally, they did not tap into the experience of senior fellows nor did they train potential successors. After 10 years of intense advocacy practice, there were no emerging leaders capable of replacing them or to give continuity to the work they had begun.

The independent living movement emerged in a more suitable environment than the existing one during the late '70s. Better communication, exchanges and experience from their leaders' recent history led to a new strategy to achieve its goals. Unlike the previous approach, the focus now shifted to self-awareness and the empowerment of individuals with disabilities to make personal and social changes.

The Brazilian independent living strategies are based on dissemination of qualitative and experiential information, support services, training of emerging leaders and the improvement of civil rights advocacy. All these have equal weight in the process and must occur concurrently.

The concept of independent living in Brazil is now beginning to be understood. For many people with disabilities it means autonomy to deal with one's own life, and to contribute to the improvement of society. The Brazilian independent living movement focuses its efforts on the values within each individual: self confidence and the "drive" to feel free and sufficiently independent to search for her/his survival with dignity.

The concept is expanding in Brazil, assuming an important role in communities and setting the standard for the movement's growth throughout Latin America. The independent living model is successful and viable not only in developed countries, but the information and empowerment that result through this movement can be "cost free" if shared under the supervision and the commitment of people with disabilities.

For additional information on the Independent Living Movement in Brazil and Latin America, the author can be contacted via e-mail at Rbbieler@aol.com

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TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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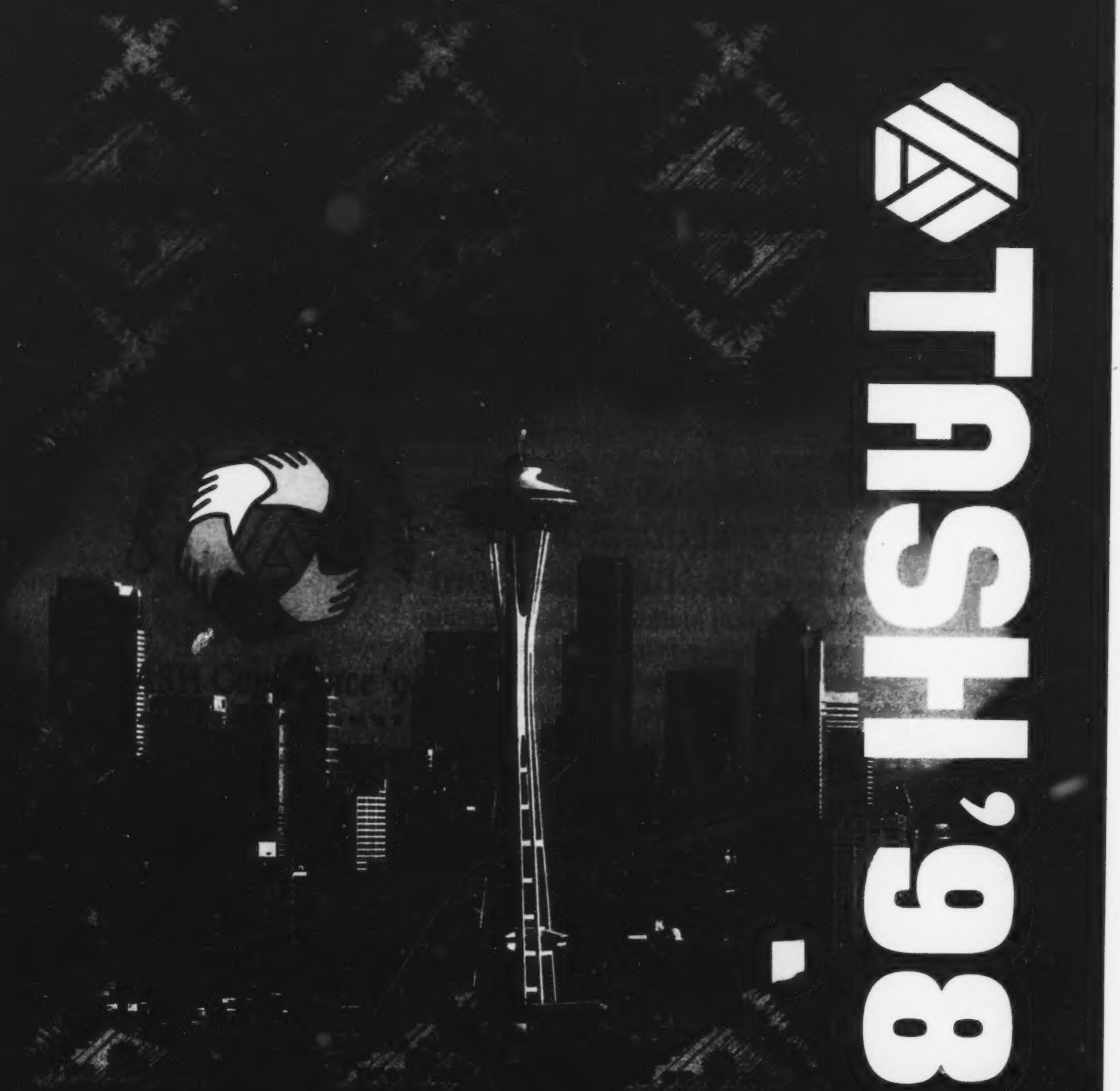
URGENT!
Dated Material Inside!
TASH Board Election
Ballot

JUNE/JULY 1998

Newsletter



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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 108 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

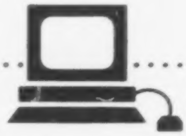
From the Executive Director

BY NANCY WEISS

Each year, the conference edition of the *Newsletter* is eagerly awaited. For members who have attended the TASH conference for years, as well as for people considering attending for the first time, this *Newsletter* provides the first peek at an invigorating array of sessions, round table discussions and special topic meetings. What you can't realize from reading the conference schedule, profiles of keynote speakers, and descriptions of sessions included in this edition of the *Newsletter*, is the incredible energy and sense of belonging that attending a TASH conference brings to participants.

Last year Kathleen Hannon, a teacher and parent from upstate New York wrote to us, "I loved the conference! When I feel isolated and alone in my beliefs, I close my eyes and put myself back in Boston – surrounded by people who live and breathe inclusion for all - it gets me through!" As parents, people with disabilities, students, administrators, researchers, teachers, adult service workers, and other disability advocates, we all struggle with the gap between our beliefs and everyday realities. I spent most of my career in the disability field feeling, as many people do, like a fish swimming upstream. Attending a TASH conference not only gives you a chance to swim with the current (if only for a few wonderful days!) but to see what's up ahead in progressive, person- and family-directed disability issues and supports.

Make plans to come to Seattle now. In addition to being an incredibly exciting city to visit, there are few experiences as confirming as spending time with upwards of 2,500 people who share your basic values, are open to all kinds of networking opportunities, and work as you do, toward making visions realities.



Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 1998 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
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- **Don't forget to visit TASH's web site at http://www.tash.org**

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Creating Futures Together

TASH Conference '98

SEATTLE, WASHINGTON

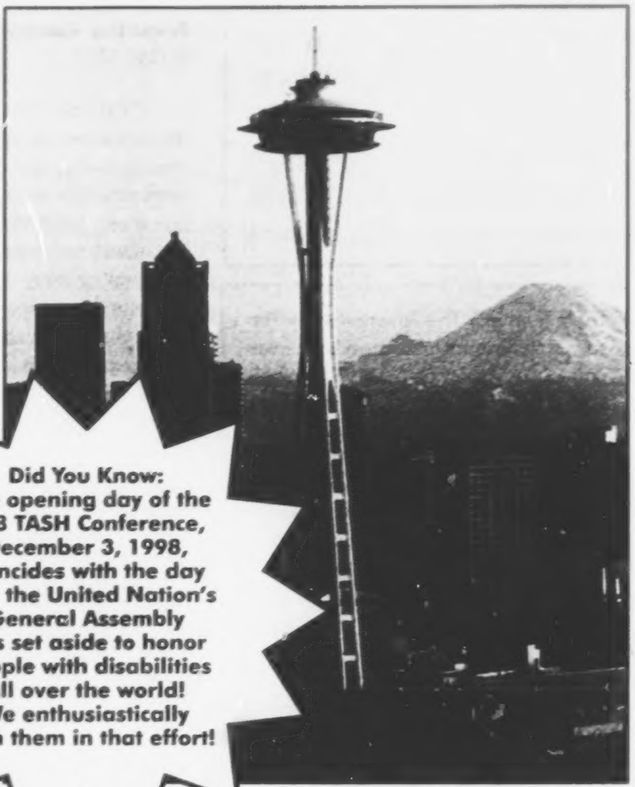
The 1998 TASH Conference is in Seattle, the place where TASH was conceived 23 years ago. No organization existed prior to the formation of TASH that believed that people with significant disabilities were capable and deserving of being fully participating citizens. TASH became the leading organization advocating for the inclusion of people with disabilities.

Now, as then, TASH continues to be at the forefront of the fight for justice, equality, and the empowerment for individuals with disabilities and their families. Join us at the TASH Annual Conference where the best of hearts and minds in the disability movement gather to provide and share cutting-edge information that inspires advocates, parents, and professionals alike to understand, support, and creatively move forward toward inclusive lives for all.

Inclusion is about all of us, with our different points of view, values, self-interests, and experiences. Come, spend time with over 2400 others who believe in the values you do, and capitalize on the synergy that is TASH. ***Create Inclusive Futures - Together!***

▼ ▼ ▼

> **"I loved the '97 TASH Conference. When I feel isolated and alone in my beliefs, I close my eyes and put myself back in Boston – surrounded by people who live and breath inclusion for all- and it gets me through."**
>
> ***— Kathleen Hannon, TASH Member***



Did You Know:
The opening day of the '98 TASH Conference, December 3, 1998, coincides with the day that the United Nation's General Assembly has set aside to honor people with disabilities all over the world! We enthusiastically join them in that effort!

For a summary of events and activites going on in Seattle, visit the website www.seeseattle.org

Look for over 450 sessions on the following topics:

Advocacy
Community Living
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Communication
Criminal Justice
Curriculum Adaptation
Deaf Culture
Dual Sensory Impairment
Early Childhood
Educational Reform
Employment and Careers
Family Issues
Functional Assessment for
  Behavior Change
Governmental Affairs
Grassroots Organizing
Higher Education
Housing /Home of Your Own
IDEA Monitoring & Enforcement
IDEA '97 Regulations
Impacting Legislation
Inclusive Education Strategies
Integrated Sports
Internet and Disability
Issues of Death and Dying
Issues of Peace and Social Change
Leisure and Recreation
Life Transitions & Changes in
  Supports for Aging Adults
Managed Care
Management Issues
MiCasa/Personal Assistance
Multicultural Issues
Paraprofessional Issues
Personnel Preparation
Positive Approaches to
  Behavior Change
Qualitative & Quantitative
  Research
Rehab Act
Related Services in Inclusive
  Education
Self-Advocacy
Self-Determination
Special Health Care in
  Inclusive Settings
Sexuality, Romance, & Dating
Spirituality
Transition from School to Work
Special Health Care Needs
Students Who Severely
  Challenge Schools,Who
  Do Not Have Labels of
  "Severe" Disabilities
Urban Education Issues

Creating Futures Together

TASH Conference '98
SEATTLE, WASHINGTON

Tentative Conference Agenda

Tuesday, December 1, 1998

8:00 PM - 10:00 PM	Registration Open

Pre-Conference Activities
Wednesday, December 2, 1998

7:30 AM - 8:45 AM	TASH Tech Registration
8:30 AM - 4:30 PM	Club TASH Day Care/Youth Activities
9:00 AM - 4:00 PM	TASH Tech Workshops
9:00 AM - 4:00 PM	TASH Chapter Development and Leadership Training
2:00 PM -8:00 PM	TASH Conference Registration
5:00 PM -7:00 PM	Opening Reception in the TASH Exhibit Hall

Thursday, December 3, 1998

7:30 AM - 1:00 PM	Registration
7:30 AM - 3:00 PM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 3:15 PM	Conference Sessions and Poster Presentations
3:30 PM - 5:30 PM	Plenary Session
5:30 PM -7:00 PM	No-Host Reception

Friday, December 4, 1998

7:30 AM - 11:00 AM	Registration
7:30 AM - 3:00 PM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 3:15 PM	Conference Sessions and Poster Presentations
3:30 PM - 5:30 PM	Plenary Session
5:30 PM - 7:00 PM	TASH Reception (sponsored by WA-TASH Chapter)

Saturday, December 5, 1998

7:30 AM - 9:00 AM	Registration
7:30 AM - 12:00 PM	TASH Exhibit Hall Open
8:30 AM - 1:00 PM	Club TASH Day Care/Youth Activities
8:00 AM - 12:45 PM	Conference Sessions and Poster Presentations

1998 TASH KEYNOTE SPEAKERS

Thursday, December 3, 1998

James Banks

James is a Professor of Education and Director of the Center for Multicultural Education at the University of Washington. He has written or edited 18 books in multicultural education and in social studies education. He is a past President of the American Educational Research Association and a past President of the National Council for the Social Studies. Early in his career, he was appointed by Secretary Casper Weinberger to serve on the National Advisory Council on Ethnic Heritage Studies of the United States Office of Education. The American Educational Research Association named James a Distinguished Scholar/Researcher on Minority Education. He has served as a consultant to school districts, professional organizations, and universities throughout the United States and abroad.

Sue Rubin

Sue is a self-advocate diagnosed with autism and moderate mental retardation. She was educated in special day classes with some degree of integration until high school. At age thirteen, Sue was testing at a 2 to 2 1/2 year level; at this time, she was introduced to facilitated communication and made slow but steady progress. Over the years, Sue's skillful use of facilitated communication has grown. She graduated from Whittier High School as a fully included student with a 3.98 GPA and scored 1370 on her SAT. Currently she is a student at Whittier College and a consultant at WAPADH, an agency that supports adults with developmental disabilities, where she demonstrates facilitated communication at monthly trainings. In addition, Sue has published two articles in the Los Angeles Times and carried the Olympic Torch in 1996 as a community hero.

Robert Williams

Recently appointed by President Clinton, Bob is the Deputy Assistant Secretary for Disability, Aging and Long Term Care Policy in the Office of the Assistant Secretary for Planning and Evaluation. For the past four years, Bob has provided strategic leadership as Commissioner of the Administration on Developmental Disabilities, a federal agency that funds activities to increase the independence, productivity, and community inclusion of Americans with developmental disabilities and their families. He is a nationally known expert on the best ways to create supports for people with multiple disabilities to live, work and play in their communities. Bob has lived with cerebral palsy since birth; he believes in community — not just as a place to live, but as a complete way of life for all.

Friday, December 4, 1998

Duane French

Duane is the first person with a significant disability to be appointed as a Division Director with the State of Alaska. Prior to his appointment as the Director of the Division of Vocational Rehabilitation, Duane was the Executive Director of Access Alaska. He has served on numerous state and

Continued on page 6

1998 TASH KEYNOTE SPEAKERS

Continued from page 5

national boards, councils and commissions over the years. Duane was the Chairperson of the Anchorage Equal Rights Commission, Very Special Arts Alaska, and the Governor's Council on Disabilities. He was a member of the Board of the National Council on Independent Living for 9 years and is currently the Legislative Committee Chairperson for the Federal Interagency Coordinating Council. Duane most proudly describes himself as a brother in the disability rights movement.

Laura Hershey

Laura is a disability rights leader, poet, writer, and trainer. She educates and agitates whenever possible to promote the rights of people with disabilities. She has organized social change campaigns and events around issues such as Social Security work disincentives, economic justice, disabled women's leadership development, and opposition to charity telethons. Her efforts have earned her a Watson Fellowship, a Colorado College honorary degree, a World Institute on Disability Fellowship, and several trips to jail for acts of civil disobedience. Laura lives in Denver, Colorado, with her partner Robin Stephens, and their dog at cat.

Judith Heumann

As Assistant Secretary of Education for the Office of Special Education and Rehabilitative Services, Judith manages the Office of Special Education Programs, the Rehabilitation Services Administration and the National Institute on Disability and Rehabilitation Research. She is among those who pioneered modern legislation recognizing that the U.S. Constitution guarantees equality of access and opportunity to persons with disabilities. Judith helped to develop legislation that became the Individuals with Disabilities Education Act. She helped draft the Americans with Disabilities Act and assisted in developing regulations for Section 504 of the Rehabilitation Act. In addition, she helped design federal and state legislation that led to the creation of more than 200 independent living centers nationwide. Judith's deep commitment to the goal of building an inclusive society comes from her own experiences; having been diagnosed with polio at the age of 18 months, she has known discrimination first hand. Judith was the first recipient of the Henry B. Betts Award for "efforts that significantly improve the quality of life for people with disabilities".

Zuhy Sayeed

Born in India, Zuhy moved to Lloydminster, Canada in 1978 where she began her career in early childhood education. As parents, Zuhy and her husband Raffath became active in the field of differing abilities in 1982, today their dedication to human rights and community living is a family commitment. Zuhy was appointed to the President's Task Force on Inclusive Education and to the United Nations Panel of Experts for the Monitoring and Implementation of the Standard Rules for the Equalization of Opportunities for persons with disabilities. She firmly believes that it is only *our collective advocacy* that will ensure that our family members are treated with fairness and dignity. Zuhy says that "this is an exciting time as we look to build bridges and discover ways that we can indeed work together as communities and nations with the collaborative vision that we share for our citizens".

— LOCATION —

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Seattle, Washington 98101
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Washington State Convention and Trade Center
(Location of Exhibits and Conference Sessions)
800 Convention Place (1 block from Sheraton)
Seattle, WA 98101 • 206-727-2814

ALTERNATE HOTELS

Seattle Hilton
Sixth and University • Seattle, Washington 98111
206-624-0500
Rate $112.00 single/double, plus 15.6% tax
$15.00 extra person
2 1/2 blocks from the Convention Center

Seattle Crown Plaza
1113 6th Avenue • Seattle, WA 98101-3048
206-464-1980
Rate: $115.00 single/double , plus 15.6% tax
2 1/2- 3 blocks from Convention Center

— AIRPORT —

Seattle-Tacoma International Airport
16 miles south of Downtown
Average cost for taxi $30, shuttle $18.00, bus $7.50

— AIR TRANSPORTATION —

Southwest Airlines will be the Official Airline for the 1998 TASH Conference

Southwest is offering a 10% discount on most of its already low fares to and from the TASH December '98 Meeting. Call (or have your professional travel agent call) the Southwest Airlines Group Meeting Desk at 1-800-433-5368, Monday – Friday 8:00 AM - 5:00 PM, and Saturday, 9:30 AM – 3:30 PM by no later than November 24, 1998 and refer to I.D. Code K1748 to take advantage of this offer. Call right away as fares are subject to terms and availability.

— GROUND TRANSPORTATION —

Grayline of Seattle Airport Express

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Frequent, fast, convenient Airport Express Service operates between Sea Tac Airport and the Seattle Sheraton and other downtown hotels. Fares are $7.50 one way or $13.00 round trip. (TASH attendees will receive $1.00 off). Please notify Gray Line at least 48 hours in advance if you require wheelchair access. For more details call Gray Line Airport Express at 206-626-6088.

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1998 Conference Social Events

Wednesday, December 2, 1998
Opening Reception
in the Exhibit Hall
5:00-7:00 PM

Thursday, December 3, 1998
Sexual Orientation Interest
and Action Group
Hospitality Hour
5:00 – 6:30

TASH Reception
Sponsored by WA-TASH Chapter
5:00-6:30

Friday, December 4, 1998
TASH No-Host Reception
5:00-6:30

RALLY
FOR INCLUSION
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DISABILITY
INCLUSION

RALLY for Inclusion!

Save time on Saturday,
December 5, 1998 • 1:00 PM

For The Annual
Post-Conference Rally!
Watch For More Details

Pre-conference Symposium on Dual Diagnosis

Introduction to Dual-Diagnosis: Assessment and Management of Psychiatirc/Behavioral Conditions in Persons with Developmental Disabilities

This special symposium, which is jointly sponsored by TASH and NADD (formerly the National Association of the Dually Diagnosed) will be facilitated by Ann R. Poindexter., a licensed physician, and Terrance McNelis, President of NADD.

Dr. Poindexter is a self-employed health care management consultant for persons with mental retardation and psychopathologic diagnoses. She has practiced, researched, and presented extensively in topics relating to psychiatric diagnosis and treatment of persons with developmental disabilities.

This highly informative, interactive symposium will outline the overall incidence and importance of behavioral/psychiatric problems in individuals with developmental disabilities. Related issues and topics to be discussed include:

- Common medical conditions, which are easily mistaken for behavioral/psychiatric conditions
- Common psychiatric conditions
- Tools to facilitate assessment and diagnosis.
- Psychotropic medications
- The support persons role in psychiatric intervention and therapy

The fee to attend this workshop is $85.00. Please use the form on pages 5-6 to register.

Forum for Canadian University and College Faculty

The first annual Forum for Canadian University and College Faculty will take on place at December 4, 1998 at 8:00-9:00. The purposes of the Forum are:

a) To provide an opportunity for TASH members who teach in Canadian Universities or Colleges to meet and share information about their educational, advocacy, and research interests,
b) To facilitate cooperative partnerships among these individuals, and
c) To discuss strategies for raising the "Canadian profile" within TASH, which has historically focused primarily on issues for people with significant disabilities within a U.S. context.

All Canadian University and College faculty and those affiliated with such institutions are encouraged to attend this historical meeting! Contact Pat Mirenda, University of British Columbia, at *pat.mirenda@ubc.ca* for additional information or to make suggestions for the Forum's agenda

TASH TECH Pre-Conference Seminars

Wednesday, December 2, 1998 9-4 (unless otherwise noted)

Registration for pre-conference seminars is in addition to conference registration. For costs see back of registration form on page 30.

T-1 Specific Strategies to Support Friendships and Community Connections between Adults with and without Developmental Disabilities.

Angela Novak Amado

Full community participation includes friendships and relationships with a wide variety of people. This workshop presents very specific strategies and practical "how-to" exercises successfully used across the country to promote community belonging, valued social roles, and friendships with community members.

T-2 Navigating the Autism Treatment Maze

Pat Mirenda

This interactive workshop will provide information about various treatment approaches for autism as well as a format for evaluating them, in a practical, non-confrontational format. The session will assist parents and professionals to understand the options available and make informed decisions about their use.

T-3 Abuse and Neglect of Individuals with Disabilities: Information for Practitioners

Wayne Crawford

This session provides an overview of abuse/neglect, examines roles and responsibilities of practitioners in the investigatory process, and explores how practitioners can act collaboratively to protect the interest of individuals with significant disabilities. An interactive format and case studies will be used.

T-4 A Toolkit for Involving People with Disabilities as Project Leaders

Marilyn Bown, Tamera Dalton, Troy Pope, Claire Mantonya, Gerald Glenn, Rich Wilson, Paul Day

The project that is the basis of this workshop is a very successful person-centered planning and training project which partnered people with and without disabilities as team members.. This workshop will include video clips, panel discussions, and a practical toolkit that includes everything you need to get started planning your own project.

T-5 Fostering Social Relationships and Building Peer Supports (9-12 AM)

Marti Snell, Rachel Janney, Kenna Colley

This workshop will present approaches for building peer support and promoting social relationships between students with and without disabilities. We will give opportunities for participants to apply concepts to case students.

T-6 Creating Inclusive Learning Communities: Curriculum, Community Building, and Reflective Practice

Lucille Zeph, Mara Sapon-Shevin, Mary Fisher

This session is designed to address some of the questions that continue to challenge families and educators who are interested in developing general education classrooms where effective educational practices combine with effective community building strategies to create learning communities where all participants are valued and successful learners.

T-7 Strategies for Successful Inclusion in the Core Academic Subjects: Grades 4-12.

Kathy Gee, Kimberly Strain

A general education, secondary teacher in the humanities and social sciences field will team with an inclusive schooling specialist to provide a lively workshop utilizing media, real classroom materials, and activities. The focus will be on creative strategies for upper elementary, middle, and high school inclusive classrooms: curricular issues, instructional strategies, adaptations, modifications, and accountability.

T-8 Alternative Assessments: Innovative State Approaches

Jacqueline Farmer Kearns, Dee Spinkston, Martha Toomey, Sarah Kennedy, Harold Kleinert, Mary Pat Farrell, Sue Bechard, Sandra Warren, John Haigh

This session will showcase innovative approaches from Kentucky, Delaware, West Virginia, Maryland, Colorado and North Carolina. Panel representatives will share this information in a full day agenda devoted to implementation issues.

T-9 Creating Creativity

John Irvin

This is an interactive workshop that presents creativity as a holistic skill that can be learned and developed. Creativity is more than just a way of thinking. It is inclusive of how we think, act and speak to one another and to ourselves. It is the skill of allowing oneself the freedom to create. Participants will receive a creativity kit to help facilitate their ongoing creativity in the work and home setting.

T-10 Providing Effective Services for Young Children with Autism: Blending Approaches to Meet Individual Needs (9-12 AM)

Ilene Schwartz, Susan Sandal, Bonnie McBride, Gusty Lee Boulware, Ann Garfinkle, Stacy Shook

The purpose of this workshop is to provide participants with an overview of strategies that are effective with young children with autism and PDD. An emphasis will be placed on blending the strengths of different disciplines to create

Continued on page 9

TASH TECH Pre-Conference Seminars

Continued from page 8

programs that are effective and appropriate for young children. Issues that will be addressed include: curricular issues, instructional strategies, and the role of peers and strategies to program for the generalization of behavior change.*

T-11 Understanding SSA Disability Benefits: It's Easier Than You Think!

Paul Selby, Connie Ferrell

Fear of losing SSI is a major concern of many individuals. The purpose of this session is to heighten awareness of both adult SSA disability programs and to present strategies for advocating for the individual with local SSA personnel.

T-12 Funding Assistive Technology for Young Children (1-4 PM)

Mary Jane Rapport

This session will provide an overview of federal laws and regulations pertaining to the provision of assistive technology devices and services to young children. Relevant legal discussions and letters from federal agencies clarifying issues will be discussed.*

T-13 Creating A Culture of Inquiry: Participatory Action Research Methodology

Gail McGregor, Hyun-Sook Park, Jean Gonsier-Gerdin, Stacy Hoffman, Elizabeth Kozleski, Dick Sagor, Chris Salisbury, Anne Smith, Susan Whaley

In this session, participants will be introduced to participatory action research methodologies that are being used in two federally funded projects that are actively exploring the link between policy, research and practice. In both of these projects, school personnel and other stakeholders are functioning as active partners and/or researchers, focusing their efforts on issues of inclusion and school reform. In the morning, participants will be introduced to the assumption's and mechanics of Action Research Methodology; in the afternoon, participants will be introduced to a participatory action research framework that empowers stakeholders in the issue under study as active change agents in bringing about school/program innovations.

T-14 From Networking to Netweaving

Gary Donaldson, Cary Griffin, Stephen Sfekas

This workshop focuses on how to transcend organizational boundaries in order to facilitate sustainable membership of persons with significant disabilities in the fabric of community life. Netweaving is a metaphor for forming new patterns of collaboration and partnerships between diverse segments and sectors of the community. Participants will learn how to leverage existing community resources by using strategies that create and add value for mutual gain.

T-15 Positive Behavioral Support and Its Application to IDEA

Rick Amado, Bobbie Vaughn

This session provides the most current resources and information regarding changes in IDEA directly related to positive behavioral support, followed by a presentation of the positive behavioral support process. The format will be very interactive, and will concentrate on contextual fit, functional assessment, and multicomponent support plans. The target audience includes families, school personnel, and other support providers.

T16- The Ethics of Touch (9-12 AM)

David Hingsburger

This workshop is aimed at persons who are required to provide physical assistance in any form to a person with a disability. This interactive workshop will address complex issues including: affectional boundaries between care providers and care recipients; provision of intimate care while maintaining respectful boundaries, avoiding potentially abusive situations or a situation that could be construed as abusive, and establishing an environment that allows people with disabilities to distinguish those who help from those who hurt. The workshop is completely practical and all questions are welcome.

T-17 Including Students with Disabilities as Fully Participating Members of the High School Community

Carol Tashie, Mary Schuh

Why students with disabilities should spend their high school career with all peers, and strategies for overcoming obstacles that cause students to spend time away from typical peers will be discussed. What students should be learning in classes; after-school; weekends; and the transition to jobs will be discussed.

TC - TASH Chapter Leadership and Development Day

This free leadership development session is for TASH Chapter Officers, chapter members and people interested in forming or joining a TASH Chapter. An interactive day, which includes lunch for pre-registrants, is planned around formal presentations on building and maintaining community support, networking and building alliances with other organizations, building and strengthening international and chapter relationships, and influencing policymakers. Participants will have opportunities to share chapter accomplishments and discuss other issues of importance to chapters.

**Registrants for T-10 or T-12 will be eligible to attend both seminars.*

1998 In-focus Strands

The TASH Conference is an incredible melding of people, topics, and information. It is the place where cutting-edge dialogue on disability issues is taking place. To help streamline some of this cutting-edge information, TASH members have taken the lead in organizing a sequence of sessions on identified topics areas. A strand simply means that the sessions will take place in the same room , for a designated period of time. In addition to these focused strands, there are other sessions on these topic area's occurring throughout the conference. Feel free to attend an entire strand, or just selected sessions within a strand.

Unlocking the Door to the Waiting List: Welcoming our Senior Caregivers

Thursday and Friday

Strand Coordinator: Nancy Meltzer

Across the nation thousands of older families continue to provide care for their loved ones with developmental disabilities. This strand focuses on the needs and interest of these senior members of our community. It will highlight the experiences of two families involved in person centered planing. The strand also addresses issues surrounding the growing waiting lists which consists primarily of aging families.

Community Living

Thursday – Saturday

Strand Coordinators: Ken Jupp, Patti Scott, Judith Snow

In this strand, presentations covering exciting and innovative approaches to living full lives in the community will be featured. Topics include housing, supports, self-determination, employment and friendships.

Creating Recreation Access Together

Thursday

Strand Coordinator: Linda Heyne

This year we devote the day to access issues (programmatic and environmental) in recreation settings. Presentations feature a therapeutic recreation model, access training, peer mentoring, use of leisure time by adults, and a model inclusive recreation program.

Criminal Justice and Persons with Disabilities as Victims of the System

Thursday- Saturday

Strand Coordinator: Barbara Ransom

This strand will not only provide information about persons with disabilities as victims, but also will offer a variety of training sessions to help persons with disabilities, their families and advocates to learn to stop the violence. Educators, providers, police officers, and persons with disabilities and advocates will explore Issues of hate crimes, sexual abuse and the victimization of children with disables.

Criminal Justice and Persons with Disabilities Accused of A Crime

Thursday-Saturday

Strand Coordinator: Barbara Ransom

This strand will discuss the impact of the criminal justice system on persons with disabilities who Are suspected and/or accused of a crime. The strand will offer panel presentations which will provide for a healthy interchange between the presenters and an opportunity for the participants to add their experiences, thoughts and ideas. Participants will benefit from sessions regarding accommodations such as alternative sentencing programs and individual justice programs.

GOVERNMENTAL AFFAIRS, PUBLIC POLICY AND GRASSROOTS ORGANIZING STRAND

(Thursday-Saturday)

Join us throughout the conference as we focus on the critical governmental, public policy and grassroots organizing issues affecting people with disabilities and their advocates.

We will follow our "tried and true" model, which includes information sessions followed by discussion, needs assessment and an action plan for our work for the coming year.

During the 1997 Conference, our members chose passage of HR 2020-MiCASA and Implementation and Enforcement of IDEA as our governmental affairs, public policy and grassroots organizing priorities for 1998. Join in setting our course for 1999 by participating in the activities of this Strand throughout the Conference.

This year, for the first time, a special call went out for presentations for the Governmental Affairs, Public Policy and Grassroots Organizing Strand. As a result, these are some of the topics to look for:*

Don't Just Sit There, Do Something!
Tia Nelis/Mike Auberger

Strategies For Building A Statewide, Grassroots Network of Parents and Self-Advocates
Marna Ayres Thompson, Robin Bolduc, Bruce Goguen, Barbara Ramsour

Achieving Autonomy Using Supported Self-Advocacy
Laura Hershey

Inclusive Education for Students with Behavior That Challenges Schools: Legal Rights and Systemic Advocacy Strategies
Kathy Boundy, Eileen Ordover

Standards Based Education Reform and Assessment: Legal and Practice Implications for Students with Disabilities
Kathy Boundy, Eileen Ordover

Transition from School to Work: Legal Rights in the High Quality Programs Designed for All Students
Kathy Boundy, Eileen Ordover

California's Coffelt Lawsuit-A Personal Perspective
Bill Coffelt

Medicaid, SSI/SSDI, Managed Care— Knowing Your Abilities and Your Policymakers
Jesse Wechsler

From Assisted Suicide to Equal Protection
Dick Sobsey

Getting Away With Murder
Dick Sobsey

"Rehabilitating" the INS: Immigration Service Compliance with Section 504
Steven Rosenbaum, Amy Kratz, Jill Dutton

Grassroots Advocacy:Planting Seeds of Change
Jadene Ransdell

From Research to Policy-A Strategies Workshop
Gary Bunch, Angela Valeo

Over-representation: Problem or Symptom
Dorothy Kerzner Lipsky, Alan Gartner, Others

Context for Political Action Within the Lives of People With Mental Disabilities
Ramon Castellblanch

Political Activism, Social Change and Disability Culture on the Internet
Michael Reynolds

TAB'S (Temporarily Able-Bodied) in a Gimp World: The Role of Partnership in Disability Advocacy
Jill Jacobs, Greg Smith

ALSO LOOK FOR WORKSHOPS ON:
The Reauthorization of Rehabilitation Act
IDEA Implementation and Enforcement Q & A
Issues for the 106th Congress
Impacting the Legislative Process
Impacting the Election Process
The Future of MiCASA
ADA Update
Much more...

**Specific dates and times of these sessions will be available at a later date.*

Employment and Transition Strand

Thursday-Saturday

Strand Coordinator: Mike Callahan

This strand will highlight over 30 sessions covering hot issues in the employment and transition of people with significant disabilities. Topics will include natural supports, choice, conversion, individualized planning and much, much more!

Continued on page 11

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Continued from page 10

Governmental Affairs, Public Policy, and Grassroots Organizing Strand

Thursday-Saturday

Strand Coordinator: Marcie Roth

Join us throughout the conference as we focus on the critical governmental, public policy and grassroots organizing issues affecting people with disabilities and their advocates. See page 10 for more complete description.

High School Inclusion: Making It Work for Everyone

Thursday

Strand Coordinators: Carol Tashie, Mary Schuh, Jeff Strully, Doug Fisher and Cheryl Jorgensen

It is 1998 and still far too many high school students with disabilities spend their days in segregated classrooms, life skills programs, and separate community-based instruction. This all day interactive, free-flowing, and provocative strand is designed for people interested in making high school inclusion a reality for all students. Share new information, gain innovative strategies, and problem solve common obstacles to achieving fully inclusive high schools. Join the strand coordinators and many others to learn, challenge, debate, and work together to make high school inclusion a reality for all students.

Models of Distance Education: Delivery of University-Level Course-work in Significant Disabilties

Thursday

Strand Coordinator: Fred Spooner

As part of this strand, models of Distance Education (e.g. two -way interactive TV, satellite enhanced CU-SEE-ME, and web based instruction) will be defined, described, and discussed for the delivery of university-level coursework in significant disabilities for within state and across state and regional dissemination.

Multicultural

Thursday and Friday

Strand Coordinator: Lynda Baumgardner

As the world grows smaller we must learn from each other the best practice in community living. Always realizing that there can be "unity in diversity". This strand features sessions focused on multicultural/international issues.

Building and Maintaining a Skilled Paraeducator Workforce

Thursday

Strand Coordinator: Anna Lou Pickett

This strand addresses administrative and career development issues that influence the recruitment, retention and performance of paraeducators. Topics addressed include guidelines for paraeducator role definition, supervisory skills required by teachers, and research findings on effective paraeducator interaction with children and youth.

Higher Education and Personnel Preparation

Thursday and Friday

Strand Coordinator: Diane Ryndak

This strand includes sessions related to restructuring preservice personnel preparation, cross-discipline preparation efforts, and university-school partnerships to facilitate change and/or preservice instruction.

Positive Approaches to Behavior Support

Thursday

Strand Coordinators: Rick Amado, Tim Knoster and Fredda Brown

This strand will feature sessions that discuss innovative practices in the development and implementation of positive supports in inclusive settings.

Sexuality Issues

Thursday-Saturday

Strand Coordinator: Ann Heler

Sexuality and sexual expression are a natural part of each of our lives. These sensitive and critical issues require awareness, respect and commitment to ensure all people have the ability and the information to act upon their choices and interests. This strand will highlight those sessions that address this critical topic.

Self-Determination

Thursday

Strand Coordinator: Tom Nerney

Self-determination is one of the hottest topics sweeping the nation. This strand will feature sessions that help to define self-determination, what it is and what it is not. Presenters include leaders in the self-determination initiative from across the country and Canada.

Special Health Care Needs

Friday

Strand Coordinator: Donna Lehr

Sessions included in this strand will focus on practices necessary for inclusion of students with special health care needs. Methods of assuring the safe provision of health care services and appropriate educational programs will be highlighted.

Spirituality

Thursday and Friday

Strand Coordinator: Alan Berger

Many people of faith, from every religious persuasion examine the issues of spirituality and disability. Inclusive religious communities have been forming to welcome people with disabilities in all aspects of religious life. This is the first time this issue has been formally explored at the TASH Conference. Join us for thought provoking sessions.

Students Who Severely Challenge Schools

Thursday

Strand Coordinators: Linda Rammler and Debbie Gilmer

This strand will focus on hot topics related to children who challenge the school system and require additional supports in the areas of family support, inclusive education, and positive approaches. A variety of sessions from students, parents, transdisciplinary team members who are involved in this issue will be included.

Urban Strand

Friday

Strand Coordinator: Nancy Zollers

This strand includes dialogue and presentations with researchers and practitioners who are working with Urban practitioners to improve schools and communities for students with and without disabilities. This year along with Lou Brown, Alison Ford, Gwen Benson, Kathy Chapman, Nancy Zollers and Mary Ann Fitzgerald are Elizabeth Fitzgerald, David Riley, Diane Ferguson, Phil Ferguson and Trish Boland, from the National Institute for Urban School Improvement.

Young Children and Families: New Views on Education and Building Community

Thursday – Saturday

Strand Coordinators: Beth Brennan, Elizabeth Irwin, Leslie Soodak

A spectrum of issues specific to young children with significant special needs will be examined throughout this strand. Information regarding legislation, practice and research in early childhood will be shared.

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Parents as Partners
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A Training Module for Proactively Building Knowledge, Understanding and Trust to Develop a Strong Family-School Partnership

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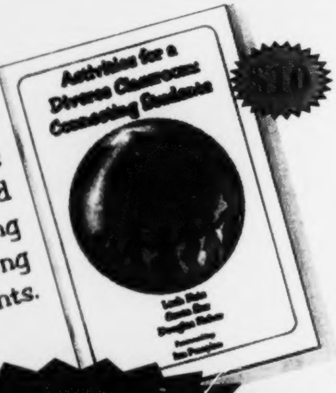
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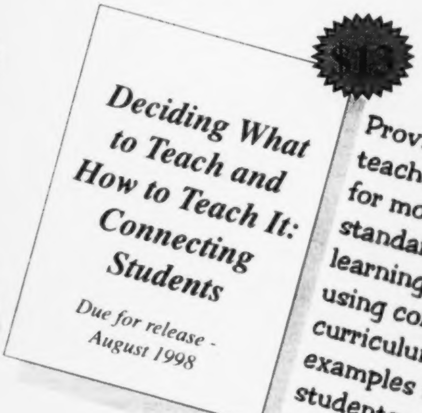
Activities for a Diverse Classroom: Connecting Students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Provides secondary teachers strategies for modifying standards-based learning activities using core curriculum. Includes examples for students with a variety of disabilities.

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Thursday, December 3, 1998 8:00 -9:00 AM

It's Our Turn: Students with Disabilities are Welcomed at Trinity College

Interest Area: Higher Education/Personnel Preparation Strand
Speaker: Mary Beth Doyle

Factors That Impact on Inclusion of Supported Employees at Work

Interest Area: Employment Strand
Speakers: Nanho S. Vander Hart, Susan M. Hamre-Nietupski

A Foot in Both Camps: Parents Who Are Also Professionals

Interest Area: Family
Speakers: Deanna Horstmeier, Ann Turnbull, Bud Fredericks, Thomas Powell

Practical Applications for Promoting Social Integration in the Workplace

Interest Area: Employment Strand
Speakers: Teresa A. Grossi, Keith Storey

Providing General Curriculum Adaptations Support through A Side-by-Side Model

Interest Area: Inclusive Education
Speakers: Susan Bashinski Nettie, Collins-Hart, Doug Eicher

Family Sensitive Services: Multicultural Perspectives

Interest Area: Multicultural/International Strand
Speakers: Yea-Shwu Alice Kang, Kathryn Haring, Jan Watts, David Lovett

Transition from Preschool to Elementary School

Interest Area: Early Childhood Strand
Speakers: Susan Gregory, Joan Watts

Therapeutic Recreation: A Person-Centered Approach

Interest Area: Leisure and Recreation Strand
Speakers: Bob Cipriano, Cynthia Driscoll

The Importance of the Arts for Children & Adults with Disabilities

Interest Area: Creative/Performing Arts
Speaker: Richard Russey

Considering Holistic Mental Health Options

Interest Area: Special Health Care Needs
Speaker: Dana Henning

Visions for Independent Living through Computerized Prompting System

Interest Area: Self-Determination
Speakers: Nancy Baesman, Bill Baesman

Assisting People with DD Who are Victims of Crime

Interest Area: Criminal Justice Strand
Speaker: James McAfee

Work-Wage Relationship and Individuals with Disabilities

Interest Area: Employment Strand
Speaker: Lou Brown

Spirituality Crackerbarrel

Interest Area: Spirituality Strand
Facilitator: Alan Berger

Self-Determination: What It Is/What It Is Not

Interest Area: Self-Determination Strand
Speaker: Tom Nerney

Transitioning to a University Campus

Interest Area: Transition Strand
Speakers: Randi Agetstein , Terri Crawford, Sheree Witt, Steve Shumaker

Advocacy-in-Action: Building Strong Effective Self-Advocacy Coalitions

Interest Area: Advocacy
Speakers: Rebecca S. Salon, Ricardo Thornton

Due Process Rights for Persons with Cognitive and Communication Disabilities

Interest Area: Criminal Justice Strand
Speakers: Dohn Hoyle, Marsha Katz

Alternatives for Community-Based Instruction: Responding to Priorities

Interest Area: Inclusive Education
Speaker: Diane Browder

Flying By The Seat of Your Pants: More Absurdities and Realities of Special Education

Interest Area: Inclusive Education
Speaker: Michael Giangreco

Thursday, December 3, 1998 8:00 -10:15 AM

Supporting People in Exercising Their Rights to Grieve

Interest Area: Ethics/Rights
Speaker: Karen Hightower

Contextual Assessment: Evaluating Students in Inclusive Educational Settings

Interest Area: Inclusive Education
Speaker: Harvey Mar

IQ Will Never Be The Same Again

Interest Area: Communication
Speakers: Anne Donnellan, Jami Davis, Sally Young

Learning to Change: Lessons from our Inclusive Learning Communities

Interest Area: Inclusive Education/Research
Speakers: Elizabeth Kozleski, Sue Chandler,Robin Brewer, Beth Schaffner, Janet Filbin, Janell Sueltz

Sea Monitoring for IDEA Compliance: Devising a System that Works

Interest Area: Inclusive Education
Speakers: Kay Lambert, Jim Comstock-Galagan

Incorporating Services for Seniors and Their Caregivers into an Existing Agency

Interest Area: Aging Strand
Speakers: Mary E. Davis, Debbie Gibson-Jaworski, Margaret Bean , Sharon Tarzia, Laurie James

Strategies for Developing Policies & Infrastructures for Improving Paraeducator Performance

Interest Area: Paraprofessional Strand
Speaker: Anna Lou Pickett

You Know Why, Let's Talk How! Changing Services to Help People Get What They Want.

Interest Area: Community Living Strand
Speakers: James Meehan, Sally Sweeney, Gail Fanjoy

Building Coalitions Will Make a Difference

Interest Area: Advocacy
Speakers: Linda Anthony, Bob Liston

A Comparison of Distance Education Models & Technologies for Severe Disabilities Personnel Prep

Interest Area: Distance Education Strand
Speakers: Fred Spooner, Barbara L. Ludlow, Belva C Collins, Martin Agran, Richard Kiefer-O'Donnell,

Thursday, December 3, 1998 9:15-10:15 AM

Facilitative Support for Members of Boards of Directors and Committees

Interest Area: Related Services
Speakers: Bob Little, Sherry Beamer, Thomas Hopkins, Charlene M. Jones, Nicole Lutz

Continued on page 14

9:15-10:15 AM Continued from page 13

Self-Determination: Translating Concepts into Support

Interest Area: Self-determination
Speakers: Linda Bambara, Christine Cole, Freya Koger

Building a Self-Advocacy Training Team

Interest Area: Ethics/Rights
Speakers: David Lord , Connie Rutherford, Bunnie Strand, Diana Robishaw, Cherie Tessier, Dale Colin, Cha Pope, Michael Raymond

Restructuring a Personnel Preparation Program: Key Steps and Lessons Learned

Interest Area: Personnel Preparation/Higher Education Strand
Speakers: William R. Sharpton, Jimmie L. Matthews

Constructing Support Plans for Students Who Have Escalating Behavior Patterns

Interest Area: Students Who Severely Challenge Schools Strand
Speaker: Lewis Jackson, Becky McClure, Michelle Padilla, Jennifer Barnes

Service, Spirituality & Leadership: Sustaining Our Work Through Power Within

Interest Area: Spirituality Strand
Speaker: Susannah Joyce

Learning to Work with Law Enforcement

Interest Area: Criminal Justice Strand
Speakers: Dianne Wolfe, Dolores Norley

Who's Listening Anyway? Parents' Perspectives on Being Heard in Inclusive Classrooms

Interest Area: Early Childhood Strand
Speakers: Leslie C. Soodak, Elizabeth Erwin

Access Recreation: Creating Access to Community Recreation Opportunities for All Kids!

Interest Area: Leisure and Recreation Strand
Speaker: Cynthia Burkhour

Whole Schooling: Connecting Inclusion to Reform in Urban & Rural Schools

Interest Area: Inclusive Education
Speakers Kim Beloin, Alan Arnold, Dominick Ferrito, J. Michael Peterson, Aremetta Rodgers, Yvonne Mayfield

A Single Mom, Twins with Autism, and Positive Behavioral Support

Interest Area: Positive Approaches Strand
Speakers: Teresa MacGregor, Shannon Kelly Keough, Brenda Fawcett

The DD Offenders Program: An Alternative Sentencing Program

Interest Area: Criminal Justice Strand
Speaker: Suzanne Lustig

Thursday, December 3, 1998 9:15 -10:45 AM

Research, Reality, and the Increasing Challenge in Aging and Advocacy

Interest Area: Advocacy
Speakers: Liz Lindley, William Dussault, Jay Umoto

Thursday, December 3, 1998 9:15 -11:30 AM

Facilitated Communication: Theory, Technique, Practice and Community

Interest Area: Communication
Speakers: Genevieve Ameling, Brad Jones, Don Shouse, Scott Newman

Strategies to Plan a Successful Future For a Person Changing Homes

Interest Area: Community Living
Speakers: Daniel Baker, Rob Horner, William Ard, Gary Sappington

Inclusion in Scandinavia, Vietnam and the U.S.: Commonalties & Differences

Interest Area: Multicultural/International Strand
Speakers: Richard A. Villa, Lee Van Tac, Jacqueline Thousand, Edvard Befring

Brothers and Sisters of People with Significant Disabilities: Concerns and Opportunities

Interest Area: Family
Speaker: Donald J. Meyer

Crackerbarrel on Employment and Transition

Interest Area: Employment and Transition Strand
Speakers: Lou Brown, Patricia Rogan, Michael Callahan

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9:15-11:30 AM Continued from page 14

"Self-Determination: Who's in Charge Anyway?"
Interest Area: Self-Determination Strand
Speaker: Sue Henshaw

Thursday, December 3, 1998 10:30-11:30 AM

Social Cognition and Friendship Development
Interest Area: Inclusive Education
Speakers: Steven R. Lyon, Becky Knickelbein

Knowing Sharon
Interest Area: Positive Approaches Strand
Speakers: Gail Mueller, Laurie Kimball

Setting The Research Agenda... Together
Interest Area: Research
Speakers: Kathleen Biersdorff, Shelley Trigg, Ryan Geake, Patricia Okahasi, Nilima Sonpal-Valias, Janet Pringle, Denise Young

Staying Safe in Your Community
Interest Area: Ethics/Rights
Speakers: David Lord, Michael Raymond, Connie Rutherford, Cherie Tessier, Diana Robishaw, Cha Pope, Dale Colin, Bunnie Strand

With a Little Help from My Friends
Interest Area: Leisure and Recreation Strand
Speakers: Teri Hough, TraceyDay

Service Learning for Students with Severe Disabilities
Interest Area: Inclusive Education
Speakers: Martha Burns, Nicholas J. Certo, Keith Storey

Teaching the Inclusive Teacher: Restructuring the Mainstreaming Course
Interest Area: Personnel Preparation/Higher Education Strand/ Research
Speakers: Kim Beloin, Mike Peterson

Looking Back at the School Experiences of Youth in Prison
Interest Area: Strand on Students Who Challenge Schools/Research
Speakers: Sharon Lynch, Philip Swicegood, Edwin Davis, Debra Price

Teaching Assistants' Talking, Learning and Creating Change
Interest Area: Paraprofessional Strand
Speakers: Mary Fisher, Dawn Birchenough, Kristen Mathewson

Fostering Grassroots Change Through Training in Eastern North Carolina
Interest Area: Distance Education Strand
Speaker: Melissa Darrow Engleman

Personnel Preparation: Perspectives of Early Intervention Practitioners
Interest Area: Early Childhood Strand
Speaker: Valerie Lava

Law Enforcement Training on Developmental Disabilities
Interest Area: Criminal Justice Strand
Speaker: Forrest Fulton

Supporting Older Parents of Adults with Developmental Disabilities
Interest Area: Aging Strand/Research
Speakers: Alan Factor

Inclusion in Faith Communities of People with Developmental Disabilities
Interest Area: Spirituality Strand
Speakers: Mair Hall

Climbing Our Mountains Together
Interest Area: Self-Determination
Speakers: Betty Jane Bertrand, Denise Winslow

Defendants with Mental Retardation: Dilemma for Criminal Justice Personnel
Interest Area: Criminal Justice Strand
Speaker: Dolores Norley

Thursday, December 3, 1998 10:30 -12:45 PM

Community Building - Seattle Style
Interest Area: Community Living Strand
Speakers: Carolyn Carlson, Archie Barrett, Larry Moss, Dick Wagner, Melanie Richardson, Susan Harmon, Rachel Kirby, Kathy Whittaker, Matt Whittaker, Thomas Whittamore

Teaming for Inclusive Education Reform
Interest Area: Inclusive Education
Speakers: Karen Zimbrich, Debra Hart

Moving Special Education Systems Forward to Support Inclusive Practices
Interest Area: Inclusive Education
Speakers: Beth Schaffner, Barbara McKenzie

Rings of Safety: Preventing Sexual Victimization of People w/ Developmental Disabilities
Interest Area: Sexuality Strand
Speaker: David Hingsburger

Hilarity Therapy
Interest Area: Personnel Preparation
Speaker: John Irvin

Principals' Project: Administrators Using Action Research to Promote Inclusive Practices
Interest Area: Inclusive Education/Research
Speakers: Christine Salisbury, Ronald Korenich, Judy Forrester, Helen Espling, Gail M. McGregor, Lucille Zeph, Elizabeth Kozleski

Our Parents Didn't Listen, Will You?
Interest Area: Governmental Affairs
Speakers: Anne Guthrie, Victoria Liska, Jack Gorelick, Linda Peyton, Sharon Johnson

Thursday, December 3, 1998 11:45 -12:45 PM

Preparing Teachers in Significant Disabilities: Literature Content vs. National Survey
Interest Area: Personnel Preparation/Higher Education Strand/ Research
Speakers: Denise Clark, Diane Ryndak

Victim Assistance to Crime Victims with Disabilities
Interest Area: Criminal Justice Strand
Speaker: Debbie O'Neil

Characteristics of Outstanding Paraeducators Working with Students w/Significant Disabilities
Interest Area: Paraprofessional Strand
Speaker: Deborah Peters Goessling

What Are They Doing Now? Exploring "Leisure Time" of Adults with Significant Disabilities
Interest Area: Leisure and Recreation Strand
Speakers: Margaret Hutchins, Adelle Renzaglia

First Step in Educational Reform: Reconceptualizing Discipline
Interest Area: Strand on Students Who Severely Challenge Schools
Speaker: Gigi DeVault

Inclusion: It's a Right and It Works!
Interest Area: Inclusive Education
Speakers: Pam Gilroy, Lynn Stonestreet, Sue Williams

Continued on page 16

— EXECUTIVE DIRECTOR —

Community Systems (CSI) is an agency dedicated to our mission of *"helping people with disabilities find happiness in their homes, communities and lives."*

CSI seeks a hands-on professional with a proven track record of success in providing state-of-the- art, high-quality supports to persons with developmental disabilities. The Executive Director is responsible for leading a multidisciplinary team of professionals, providing clinical guidance and financial management.

REQUIREMENTS INCLUDE: Advanced degree plus 10 years related experience. Knowledge of self-determination, budget management, and use of a personal computer. Please send vitae/resume and letter of interest to:

Executive Search
295 Alvord Park Road
Torrington, CT 06790

CSI is an AA, EOE employer supporting workplace diversity.

11:45 AM - 12:45 PM Continued from page 15

As Families Would Have It: Effective Family Support Policy
Interest Area: Family
Speaker: Susan Yuan

Connecting University Students with Families through Supportive, Meaningful Internet Activity
Interest Area: Distance Education Strand
Speakers: Emily Watts, Ching-Jung Lin

Teachers' Conceptions of Inclusive Education in the Malaysian Educational System
Interest Area: Multicultural/International Strand /Research
Speaker: Winny Bosi

The ADA and Reasonable Accommodations for Persons w/ Disabilities in the Criminal Justice System
Interest Area: Criminal Justice Strand
Speaker: Frank Laski

Through the Eyes of Team Members: The Meaning of Positive Approaches
Interest Area: Positive Approaches Strand
Speakers: Linda Bambara, Freya Koger, Ophelia Gomez

Multiple Pathways to Meet the Needs of Students in Urban School Districts
Interest Area: Urban Issues
Speakers: Jennifer J. Coots, Marquita Grenot-Scheyer, Mary Falvey, Kathryn Bishop-Smith

Creating Postsecondary Options: Issues & Strategies from the Field
Interest Area: Transition Strand
Speakers: Marcia C. Arceneaux, William R. Sharpton

Faith and Individuals with Disabilities: Inclusive Church Congregations
Interest Area: Spirituality Strand
Speaker: Kimberly Farrington

Moving Beyond Awareness: Teaching Disability Culture and Civil Rights
Interest Area: Self-Determination
Speaker: Jill Crawford

Enhancing Services for Fathers of Children with Disabilities
Interest Area: Family
Speakers: James May, Paul Blair, Robert Poretz-Rosoles, Ray Gonzales

Cooperative Learning and Inclusion: Making It Work for All Students
Interest Area: Inclusive Education
Speaker: Mara Sapon-Shevin

Reclaiming Our Lives: Self-Directed Support Brokerage
Interest Area: Self-Determination Strand
Speakers: Laurie Powers, Randal Fulgham, Rosella Samuelson, Diann Drummund, Jan Staehely

Plan Wars: Resolving Tensions in Person Centered-Directed Planning for Employment
Interest Area: Employment Strand
Speaker: Norciva Geddie Shumpert

Public Sector Careers in Seattle, King County and Washington State
Interest Area: Employment Strand
Speakers: Candace T. O'Neill, Heather Weldon, Rhonda Bell, Ray Jensen

Working Together: Decision Making Processes for All IFSP Team Members
Interest Area: Early Childhood Strand
Speakers: Jacqui Vanhorn , Leau Phillips

Supporting Families Today in Their Communities: The New Family Support Program in Washington
Interest Area: Family
Speakers: Susie Schaefer, Adina Angle, Allison Middleton, Steve Elliott, Elaine Shah-Bragg

Thursday, December 3, 1998 11:45 -2:00 PM

Doing Research in the Time of Disability Rights
Interest Area: Research
Speakers: Douglas Biklen, Ellen Brantlinger, Christopher Kliewer, Susan Rubin

Thursday, December 3, 1998 1:00-2:00 PM

Training Person-Centered Planning Facilitators: Challenges of a Paradigm Shift
Interest Area: Community Living Strand
Speakers: Angela Novak Amado, Marijo McBride

Jimmy Tanahashi's Gift: Working for Dharma in the West
Interest Area: Spirituality Strand
Speaker: Bonnie Shoultz

Using Disability Humor to Promote Awareness & Inclusive Practices
Interest Area: Inclusive Education
Speakers: Robin Smith, Mara Sapon-Shevin

Stories from Families of Children w/ Significant Disabilities & Challenging Behavior
Interest Area: Positive Approaches Strand
Speakers: Bobbie J. Vaughn, Lise Fox, Glen Dunlap

Understanding the Process of Change: Catalysts and Leadership in Program Conversion
Interest Area: Employment Strand
Speakers: John Butterworth, Patricia Rogan

Continued on page 17

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1:00-2:00 PM Continued from page 16

Helping or Hovering: Paraeducators in Inclusive Classrooms
Interest Area: Paraprofessional Strand
Speaker: Mary Fitzgerald

Resources for People with Disabilities Who are Sexually Abused
Interest Area: Criminal Justice Strand
Speaker: Leigh Ann Reynolds

Reflections on Support "Systems"
Interest Area: Students Who Severely Challenge Schools Strand
Speakers: Linda Rammler, Deborah A. Gilmer, Cathy Apfel

Working the Media: A Grassroots Strategy
Interest Area: Communication
Speakers: Jennifer Burnett, Marsha Katz, Steve Verriden

Transition to Community Life in Distressed Neighborhoods: A School/Agency Partnership
Interest Area: Transition Strand
Speakers: Fredda Rosen, Geoffrey Lloyd, Emily B. Ellis

"Don't Forget the Fun Developing Inclusive Recreation in Your Coummunity"
Interest Area: Leisure and Recreation Strand
Speakers: Maria Paiewonsky, Susan M. Tufts

Challenges and Strategies for Preparing Personnel to Work in Rural Settings
Interest Area: Distance Education Strand
Speakers: Phil Wilson, Emily Watts, Harold L. Kleinert, James A. Knoll, Jennifer Grisham-Brown

Reach for IT
Interest Area: Self-Determination
Speaker: Dick Hosty

Achieving Citizenship for All - The Role of Individualized Funding
Interest Area: Self-Determination Strand
Speakers: Brian Salisbury, Christine Gordon

Curricular Adaptations for Students with Significant Challenges During Difficult Periods
Interest Area: Inclusive Education
Speakers: June Downing, Diane Browder

Thursday, December 3, 1998 1:00-3:15 PM

Innovative Partnerships for Inclusion: Parents-University-School
Interest Area: Personnel Preparation/Higher Education Strand
Speakers: Kathleen Campbell, Diana Walsh

Community Building & Circles of Support
Interest Area: Family
Speakers: Lindy Stormberg-O'Keeffe, Michele Lehosky, Betty Johnston, Roberta Reesman

Early Intervention Opportunities and Challenges
Interest Area: Early Childhood Strand
Speakers: Kathy Sykes, Michael Moore, Eileen Keenan

Perspectives of Family Members and Students Supported by Medical Technology on Transition
Interest Area: Transition Strand
Speakers: H. Rutherford Turnbull, Amanda Reichard, Gardner Umbarge, Mary Morningstar

Is it Either/Or? No! "Systematic" and "Inclusive" Go Together
Interest Area: Inclusive Education
Speakers: Kathleen Gee, Lori Goetz, Jacki L. Anderson, Barbara Thompson

Resourcefulness, Resiliency and Resources: Tools for Inclusion in Aotearoa/New Zealand
Interest Area: Multicultural/International Strand
Speakers: Luanna Meyer, Alison Kearne, Roseanna Bourke, Jill Bevan-Brown, Janis Carroll-Lind, Lani Durnil-Moazami, Masoud Moazami

Microsoft Active Accessibility
Interest Area: Technology
Speakers: Marina Rosen, Gary Moulton

Planning with Senior Families & Their Adult Children with Disabilities
Interest Area: Aging Strand
Speakers: Nancy Meltzer, Delia Cano, Alan Factor, Lupita Cano, Sally Sehmsdorf, Nadean Robert, David Bass

Provider Issues Relating to Consumer Choice
Interest Area: Employment Strand
Speakers: Michael Callahan, Abby Cooper

MiCASA: The Campaign for REAL Choice
Interest Area: Advocacy
Speakers: Michael Auberger, Woody Osburn, Linda Anthony, Bob Liston

Effectively Managing Support Staff
Interest Area: Management Issues
Speaker: Denise Mautz

Sex and the Single Self-Advocate
Interest Area: Sexuality Strand
Speakers: Michael J. Owens, Sheila Scott, Martha Kline, Deborah Robinson, Dan Kline, Lou Ann Ross, Lynn Balochilo, Jo Ann Myer, Steve Dorsey

Thursday, December 3, 1998 2:15 PM 3:15 PM

Functional & Inclusive Curriculum Getting the Balance Right
Interest Area: Inclusive Education
Speakers: Donna Lehr, Patricia K. McDaid, Regis C. Miller

The State of Family Support in Washington
Interest Area: Research
Speakers: Paul Froese, Lyle T. Romer, Matthew Swank

Involving Family Members and Individuals with Disabilities in Preservice Programs
Interest Area: Distance Education Strand
Speakers: Barbara L. Ludlow, Michael Duff, Steven Pavlovic, Sara Brannan

Positive Behavioral Support for Students Who Challenge Schools But Do Not Have Significant Disabilities
Interest Area: Students Who Severely Challenge Schools Strand
Speakers: Sharon Lohrmann-O'Rourke, Tim P. Knoster

Fremont Time - Community Building through Skills Exchange
Interest Area: Community Living Strand
Speakers: Melanie Richardson, Deanne Hunt, Bitten Fester, Don Cavenaugh, Martha Hinojose

Leadership for Inclusive & Continuous School Improvement
Interest Area: Inclusive Education
Speakers: Janell Sueltz, Christi Smith, Dan Vallez, Alison Boggs

Positive Behavioral Support w/Families of Diverse Cultural Backgrounds, Issues & Considerations
Interest Area: Positive Approaches Strand
Speakers: Bobbie J. Vaughn, Glen Dunlap, Ann Turnbull

Continued on page 18

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2:15-3:15 PM Continued from page 17

Special Education Monitoring & Compliance
Interest Area: Advocacy
Speaker: Leslie Seid Margolis

Supervising Paraeductors in School Settings: A Team Approach
Interest Area: Paraprofessional Strand
Speaker: Kent Gerlach

Treatment Acceptability of Choice Making Interventions for Adults w/ Developmental Disabilities
Interest Area: Communicaiton
Speakers: Pat Mirenda, Francesca Barth

A Retrospective Study of Changes in the Field From 1991-98
Interest Area: Personnel Preparation/Research
Speakers: Joanne Eichinger, Robert Ike, Kelly Evans, June Downing, Amy Feck

Providers & the Justice System: Acting in Your Client's/Student's Best Interest
Interest Area: Criminal Justice Strand
Speaker: Jane Dalen

Resources for Victims with Disabilities
Interest Area: Criminal Justice Strand
Speaker: Beverly Frantz

My Voice—My Choice
Interest Area: Self-Determination Strand
Speakers: John Agosta, Kerri Melda

Interest and Action Meeting for Leisure and Recreation
Interest Area: Leisure and Recreation Strand
Facilitator: Cynthia Burkhour

Inclusive Education Systems Change...Looks Messy, But it's Really Chaos
Interest Area: Inclusive Education
Speakers: Lucille Zeph, David Noble Stockford, Mark Fairman

Person Centered Job Development: No More Square Pegs in Round Holes
Interest Area: Employment Strand
Speaker: Paul Selby

Delaware Alternative Assessment
Interest Area: Inclusive Education
Speakers: Martha Toomey, Mary Ann Mieczkowski, Donald L. Peters

—Thursday Poster Sessions—

Thursday
Poster Session I
9:00 -11:00 AM

An Example of Individualizing Computer Assisted Instruction
Interest Area: Positive Approaches
Speakers John Foshay

The Role of Dispute Resolution in Managed Care Conflicts
Interest Area: Ethics/Rights
Speakers: Jeanne Durr, Laura Schumacher

Experiences of Community: "It's the day-to-day living that matters."
Interest Area: Research
Speaker: Joanna Royce-Davis

Identity Management Issues Persons with DD Who Identify as Lesbian, Gay or Bisexual
Interest Area: Sexuality/Sexual Expression
Speaker: Scott Thompson

Florida Outreach Project for Individuals w/Deaf-Blindness: A Program Description
Interest Area: Students Who Severely Challenge Schools
Speakers: Melinda Morrison, John Polefko, Laurie L. Trulzi, Donna Gilles

What a Good IDEA! The Evolution of a Parent Manual
Interest Area: Advocacy
Speakers: Charlene Comstock-Galagan, Kay Lambert, Denise Brady

A Comprehensive Service Delivery Program for A Woman with Deaf/Blindness
Interest Area: Community Living
Speaker: Sarah Wilson

Parents as Care Managers - Results and Expansion
Interst Area: Family
Speakers: Joan Grauman, Deb Hobbs, Sue Dow

Discovering Connections: A Guide to the Fun of Bridging Disability Differences
Interest Area: Community Living
Speaker: Linda Hill

Inclusive Network of Kansas for Students with Severe Disabilities: A Statewide Field-Based Consultant Model
Interest Area: Personnel Preparation/Research
Speakers: Gwen Beegle, Donna Wickham, Susan Bashinski, Joan Houghton, Margy Hornback, Jami Sweeney

Thursday
Poster Session II
1:00 - 3:00 PM

Human Rights: Understanding and Using the Laws
Interest Area: Ethics and Rights
Speaker: Patricia Okahasi

Healing Reflections: A Reason to Change
Interest Area: Urban Issues
Speakers: Ann Marie Campbell, Barbara Prince

The Lifestyle Development Process: An 8 Year Overview
Interest Area: Positive Approaches
Speakers: Tracy Kand-Borg, Ken Brown, Bonita Holman, Michael Colins, Selena Chong, Christine White, Leslie Jones, Claudette Sandecki

The Children's Link Society
Interest Area: Family
Speakers: Brenda McInnis, Kim Kruger

Supports for Children with Deaf/Blindness, Their Families, and Schools
Interest Area: Students Who Severely Challenge Schools
Speakers: David Lovett, Kathryn Haring, Jan Watts

Positive Approaches to Learning: Teaching About Concept Development
Interest Area: Communication
Speaker: Masoud Moazami

Catholic School Inclusion Initiatives
Interest Area: Inclusive Education
Speakers: Patt Jones, Aimee Fellows, Father Joseph Sileo, Dorothy Thayer

Will You Work For Me? Self-Determined Hiring Practices
Interst Area: Self-Determination
Speaker: Nancy Meyers

1998 TASH Annual Conference

Take time to experience the taste, sights and sounds that have made Seattle one of the premier convention destinations in the country! Check out one, or both, of these exciting tour events during your stay in Seattle.

Grapes & Hops Tour

Enjoy the scenery of rural Seattle as you travel to the Columbia Winery and Redhook Brewery. First, you tour charming Redhook Brewery. Try several complimentary hearty microbrews, while learning the beer making process and the history of the Redhook Brewery. You'll receive a Redhook Brewery souvenir glass during the tour.

Next, tour the spectacular Columbia Winery. You'll discover Columbia Winery's history and how this winery produces such award-winning wines. After the tour, enjoy complimentary wine tasting - a feast for the senses.

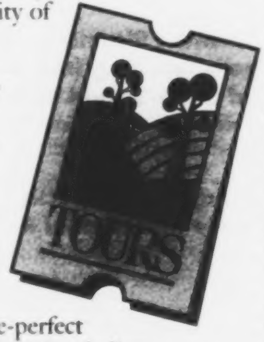
Date: Saturday, December 5th; tour departs at 2:00 PM
Duration: Approximately 5 hours
Cost: $42.00 (includes a box lunch)

Seattle City Tour

You will learn why Seattle has been named one of America's most livable cities! Our friendly and informative tour guide will give historical background on the area, point out interesting landmarks, as well as give insider tips on special shopping and sightseeing areas.

Included in the tour is Freeway Park and the bustling Pike Place Market where Seattleites shop for produce and art. You'll see historic Pioneer Square which was settled in 1852 and is now home to Seattle's top art galleries; the International District, heart of Seattle's Asian community; and the magnificent gothic-style buildings on the 680-acre University of Washington campus.

Next, explore the Hiram Chittenden Locks, the passageway between saltwater and fresh for 78,000 vessels a year. Inspect the fish ladders where thousands of salmon travel upstream to spawn. Visit a local coffee roasting plant and learn all about coffee roasting. Finish your tour at one last stop - Magnolia Bluff neighborhood - north of the city, for picture-perfect views of Elliott Bay and the stunning city skyline.



Date: Sunday, December 6th; tour departs at 9:00 AM
Duration: Approximately 3 hours
Cost: $28.00

Innovations

Invitation for Submissions

About the Series

Innovations is a publication of the American Association on Mental Retardation that brings research to practice. Designed for busy practitioners, **Innovations** translates research findings into clear, usable ideas. Each issue is devoted to one topic. Recent issues have included:

Teaching Students in Inclusive Settings	by MaryAnn Demchak
Teaching Self-Management to Elementary Students	by King-Sears & Carpenter
Designing Positive Behavioral Support Plans	by Bambara & Knoster
Increasing Variety in Adult Life	by Daniel Steere

CALL FOR CONTRIBUTORS

Submissions of proposals for the 1999 series are invited. Potential contributors are requested to prepare a 2-3 page proposal including a description of the topic and its importance, an outline of the content and references. If a proposal is accepted, a full manuscript will be invited for review. The deadline for the next round of review is **November 1, 1998**. Mail 15 copies of the proposal to Diane Browder, Editor of **Innovations**, Department of Counseling, Special Education, and Child Development, University of North Carolina at Charlotte, 9201 University City Boulevard, Charlotte, NC
28223-0001

Friday, December 4, 1998 8:00 -9:00 AM

Related Services in Inclusive Classrooms: Four Years of Research
Interest Area: Related Services/Research
Speakers: Michael Giangreco, Susan Edelman

MAPS As A Planning Tool: What Works? What Doesn't? Says Who?
Interest Area: Inclusive Education
Speakers: Meg Grigal, Carol Quirk, Sue Manos

Transition Planning: A Dialogue about Teaching Interpersonal and Socio-Sexual Skills
Interest Area: Transition Strand
Speaker: Wanda J Blanchett

Employers' Perspectives on Hiring People with Mental Retardation
Interest Area: Employment Strand/Research
Speakers: Deborah Olson, Andrea Cioffi

Make a Connection: A Social Connection Service for People with Disabilities
Interest Area: Sexuality Strand
Speakers: Ryan Geake, Denise Young

Advocacy Building in Cultural Communities
Interest Area: Multicultural/International Strand
Speakers: Elaine Schab-Bragg, Shan Shan Chein, Regina Harris, Loxy Brazelton

Maryland's Ask Me! Project
Interest Area: Positive Approaches
Speakers: Mindy Morrell, Carlo Harris, Luciene Pisa, Gordon Bonham, Joan Rumenap

Hey, What's The Big IDEA? Implementing IDEA's Discipline Requirements
Interest Area: Positive Approaches
Speakers: Robin Brewer

You Gotta Wanna: The Philadelphia Inclusion Network
Interest Area: Early Childhood Strand
Speakers: Suzanne Milroy, Philippa H. Campbell, Lisa Schneider, Lillian M. McCuen

The 5 Phases of the Criminal Justice System: From Initial Appearance Through the Correctional System
Interest Area: Criminal Justice Strand
Speaker: Suzanne Lustig

Forum for Canadian University and College Faculty
Higher Education
Facilitator: Pat Mirenda

Person Centered Behavioral Support: The Key to Meaningful Change
Interest Area: Positive Approaches
Speakers: Craig Miner, Paul Bates

Community Living Partnership: Working Together Dreams Can Come True
Interest Area: Community Living Strand
Speakers: Bob Herne, Rosalee Iadarola

Specialized Physical Health Care Procedures: Survey of Service Delivery
Interest Area: Special Health Care Needs Strand
Speaker: Josephine Chappell

Success in College for a Non-Verbal Autistic Student - What it Takes
Interest Area: Higher Education/Personnel Preparation Strand
Speakers Rita Rubin, Steve Boyer, Karen Kilk, Susan Rubin

Inclusive Middle School Math? A Multi-Level Approach
Interest Area: Inclusive Education
Speaker: Bobbi Schnorr

From Dreams to Reality - My Journey
Interest Area: Community Living
Speakers: Jean M. Millen, Jill Langevin, Nancy Boyle, T.J. Hill, Marni Healy

A Database of Inclusion Teaching & Learning Resources
Interest Area: Inclusive Education
Speakers: Teri Howatt, Dee Dickinson

Peer and Mentor Support via the Internet
Interest Area: Transition Strand
Speaker: Sheryl Burgstahler

Safety and Your Rights
Interest Area: Criminal Justice Strand
Speakers: Cherie Tessier, Dale Colin, Connie Rutherford, Diana Robishaw, Michael Raymond

Building Community Circles in Detroit
Interest Area: Urban Issues
Speakers: George Kwaka-Ntiri, Sharon Murphy, Maude Freeman, J. Michael Peterson

Research in Supported Employment
Interest Area: Employment Strand
Speakers: David W. Test, Wendy M. Wood

Connecting Urban Youth: Inclusion from the Inside Out
Interest Area: Urban Issues Strand
Speakers: Kathy Chapman, Rebecca S. Salon, Norris Johnson, Gail Hilliard-Nelson

Statewide Systems Change: Lessons Learned from Multiple State Projects
Interest Area: Inclusive Education
Speakers: Christine Salisbury, Gail M. McGregor, William R. Sharpton, Wayne Fox

Sibshops: Getting Started
Interest Area: Family
Speaker: Donald J. Meyer

Friday, December 4, 1998 8:00-10:15 AM

Supporting Communication Technology Using Students in General Education: A Holistic Approach
Interest Area: Communication
Speakers: Catherine Sementelli, Aileen Arai, Victoria H. Jones, Lynn Haynes, Stephanie Gulla

Leadership Today: Partners in Effective Decision-Making
Interest Area: Advocacy
Speakers: Sandra Mak, Tia Nelis, Gail Davis, Kathleen Biersdorff

Successes & Challenges in Building Supports for Facilitated Communication
Interest Area: Communication
Speakers: Harvey Lavoy, Pascal Cravedi-Cheg

Unlocking the Waiting List: Creating Futures For All People
Interest Area: Aging Strand
Speakers: Judy Liddell, Bill Sellars, Janet Adams

Spirituality, Peacemaking and Community Building...or the Purpose of Life
Interest Area: Spirituality Strand
Speakers: Craig A. Michaels, Denise L. Ferrara

Building Sustainable Communities of Support
Interest Area: Positive Approaches
Speakers: Don Shouse, Genevieve Ameling, Brad Jones, Scott Newman

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8:00-10:15 AM Continued from page 20

The Behavior-Communication Link
Interest Area: Positive Approaches
Speakers: Kim Davis, Susan Dixon

Friday, December 4, 1998 9:15 -10:15 AM

Family Managed Employment: A Look at Voucher Projects in Washington
Interest Area: Employment Strand
Speakers: Lyn McIntyre, Cesilee Coulson

South Carolina's Change to a Person-Centered Model for Adult Supports & Positive Behavior Supports
Interest Area: Management Issues
Speakers: David Rotholz, Ron Dozier

Providing Related Services in Rural and Remote School Districts
Interest Area: Related Services
Speakers: MaryAnn Demchak, Carl R. Morgan

Early Childhood Services: Families' Experiences and Perceptions
Interest Area: Research
Speakers: Kathryn Haring, David Lovett

Consumer Planning Partnership Project: Choice & Self-Determination in the Rehabilitation System
Interest Area: Self-Determination
Speakers: Brigid Flannery, Roz Slovic

What Really Makes the Difference?
Interest Area: Employment Strand
Speakers: Patricia Rogan, Susan Rinne, Michelle Howard Carie

Longitudinal Investigation of Emerging Behavior State Patterns
Interest Area: Early Childhood Strand/Research
Speakers: Doug Guess, Sally I. Roberts

The Cultural Audit of School Services for Maori Children with Special Needs
Interest Area: Multicultural/International Strand
Speaker: Jill Bevan-Brown

Technology in Transition Planning: Suggestions for Stakeholders
Interest Area: Transition Strand
Speakers: Colleen Thoma, Mary F. Held

You've got a choice...

Melding Module
for facilitating staff development

Melding Guide
for self-development

Skill Development
Products for Partner Teachers
Supervising Paraeducators Who Support
Students with Special Needs

Processes and Tools to:
- facilitate negotiation of roles and responsibilities
- foster initial and on-going communication
- promote collaborative problem solving

That result in:
- a positive working relationship between partner teacher and instructional paraprofessional
- best possible services and supports for students with **special needs**

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The Role for Self-Advocates in Ensuring Reasonable Accommodation in the Criminal Justice System
Interest Area: Criminal Justice Strand
Speakers: Liz Obermayer

We've Come A Long Way, Or Have We?
Interest Area: Special Health Care Needs Strand
Speakers: Angie Hawkins, Josephine Chappell

Urban Issues
Interest Area: Urban Issues Strand
Speakers: Nancy J. Zollers, Arun Ramanathan

Curricular, Behavioral and Peer Supports: Success in the Middle School
Interest Area: Inclusive Education
Speakers: Ben Adams, Renee Adams, Calab Adams, Lori Eshilian

Meaningful Transition Plans for Youth with Profound Disabilities Using Behavior State Assessment
Interest Area: Transition Strand
Speakers: Barbara Guy, Donna Suter, Wendy Bills, Tammy Salerno, GaryFritz

Friday, December 4, 1998 9:15-11:30 AM

Roundtable Discussion on National, State, and Local Policy Trends: Downsizing and Closing of Institutions
Invited Facilitators: Frank Laski, William Coffelt

Alex's Gift: "A Way to Belong" - Strategies for Inclusion
Interest Area: Inclusive Education
Speakers: Cheryl Nickels, Rachel Nickels, Tara Todhunter, Niki Owens, Mark Todhunter

Using Transition Principles to Prepare Doctoral Graduates for Employment in Higher Education
Interest Area: Higher Education/Personnel Preparation Strand
Speakers: Michael Brady, Fred Spooner, Diane Baumgart, Diane Ryndak

Cultural Competency: Addressing the Needs of Non-Heterosexual Adolescents/Young Adults
Interest Area: Sexuality Strand
Speakers: Wanda J. Blanchett, Bonnie Shoultz

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9:15-11:30 AM Continued from page 21

Supporting Students with Challenging Behaviors and Learning in Inclusive Settings
Interest Area: Positive Approaches
Speakers: Deborah L. Hedeen, Barbara Ayres

Positive Behavioral Support: Demonstration of an Interactive Trainer's Packet
Interest Area: Positive Approaches
Speakers: Denise Poston, Gigi DeVault

The National Supported Employment Evaluation
Interest Area: Employment Strand/Research
Speakers: David Mank, Mike Ruef, Becky Banks, Susan Rinne, Grant Revell, Patricia Rogan

Understanding Violence in the Lives of People w/DD: Reducing the Risks
Interest Area: Criminal Justice Strand
Speaker: Richard Sobsey

Functional Assessment and Behavioral Support: An IDEA Whose Time Has Come
Interest Area: Positive Approaches
Speakers: Tim P. Knoster, Linda Bambara, Rob O'Neill

Friday, December 4, 1998 10:00 AM-3:00 PM

Tour of Homes
Interest Area: Community Living Strand
Speakers: Diane McCalmon, Forest Wetzel, Sue Closser, Jan Navarre, Rene Roos, Gil Roos

Friday, December 4, 1998 10:30-11:30 AM

Speaking Up for Us Again: Rebuilding Maine's Self-Advocacy Network
Interest Area: Advocacy
Speakers: Laurie Kimball, Louis D. Bergeron

Systems Change at the Local Level: Local Government Funders Changeover to Supported Employment
Interest Area: Employment Strand
Speakers: Joyce Dean, Mary L. Strehlow, Jane W. Boone

What You Can Do
Interest Area: Criminal Justice Strand
Speaker: Jeri Houchins

Teacher Reflection Groups: Quality Educational Programs for ALL Students
Interest Area Inclusive Education/Research
Speaker: Margy Hornback

Adult Medication & The Goldilocks Principle: "Getting It Just Right" in Inclusive Settings
Interest Area: Advocacy
Speakers: Marquita Grenot-Scheyer, Susan Leonard-Giesen

Success in Employment - What Role Does Educational Background Play?
Interest Area: Employment Strand/Research
Speakers: Elizabeth Dolman, Sandra Mak, Nilima Sonpal-Valias

Curriculum & Instruction in General Education: Are These Best Practices?
Interest Area: Inclusive Education
Speaker: Martin Agran

Advocating Oral Health Change for People with Disabilities
Interest Area: Special Health Care Needs Strand
Speaker: Frank Farrington

School Linked Integrated Services: Evidence of Change at the Local Level
Interest Area: Early Childhood Strand
Speaker: Christine Salisbury

"My Life, My Choices: Self Determination in NJ"
Interest Area: Community Living Strand
Speakers: Kenn Jupp, Patti Scott, Brad Goldman

Open Forum on "Access to Outdoor Recreation"
Interest Area: Leisure and Recreation
Facilitator: Cynthia Burkhour
(see page 39 for description)

MiCASA: The Struggle to Free Our People
Interest Area: Advocacy
Speakers: Michael Auberger, Linda Anthony, Bob Liston

Focusing on the Point of Transition
Interest Area: Transition Strand
Speakers: Nicholas J. Certo, Eve Muller, Kimberley Smalley, Ian Pumpian, Denise Mautz, Caren Sax

Italy: A National Commitment
Interest Area: Multicultural/International Strand
Speaker: Carol Berrigan

"Cool Bodies?" Disability and "Girl Culture" in a Scout Troop
Interest Area: Research
Speaker: Perri Harris

Using Newsletters As An Advocacy Tool
Interest Area: Advocacy
Speaker: Linda Hertell

Welcome to a "Dream Catchers" Gathering
Interest Area: Positive Approaches
Speaker: Jean M. Millen

Friday, December 4, 1998 10:00-12:00 PM

Creating Non-School Work Opportunities for Students with Disabilities in Urban High Schools
Interest Area: Urban Issues Strand
Speakers: Lou Brown, Deloras Freeman, Anne C. Smith, Tracy Knight

Friday, December 4, 1998 10:30-12:45 PM

Empowering Staff to Provide Effective Support in Inclusive Settings
Interest Area: Inclusive Education
Speakers: Katherine F. Doering, Jean Gonsier-Gerdin

Facilitated Communication & Memoir: Events in the Life of Eugene Marcus
Interest Area: Communication
Speakers: David Marcus, Eugene Marcus

Empowerment: From Buzzword to Practice
Interest Area: Independent Living
Speakers: Jennifer Burnett, Steve Verriden, Linda Anthony

Strategies for Attaining Alertness/Attention in Children with Significant Disabilities
Interest Area: Students Who Severely Challenge the System
Speakers: Robin Greenfield, Gail Brown

Friday, December 4, 1998 11:45 -12:45 PM

Partnerships Between Local Public Schools and Teacher Preparation Colleges
Interest Area: Higher Education/Personnel Preparation Strand
Speaker: Mary Beth Doyle

Continued on page 23

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11:45 AM - 12:45 PM Continued from page 22

Restructuring and Professional Practices That Foster Inclusive, Standards-based Schools
Interest Area: Inclusive Education/Research
Speakers: Janet Filbin, Linda Montoya, Mary Rose Keyes, John McKinney

Health Matters: Health Issues and Women with Disabilities
Interest Area: Special Health Care Health Strand
Speakers: Loraine Luterbach, Nilima Sonpal-Valias, Janet Pringle, Denise Young

Integration in Employment and Transition: Current Research & Future Needs
Interest Area: Employment Strand/ Research
Speakers: Keith Storey, Janis Chadsey, Nicholas J. Certo, Denise Mautz, Carolyn Hughes

Making Connections Through Mentoring
Interest Area: Inclusive Education
Speakers: Nora O'Farrell, Lori Goetz

Roundtable Discussion for Advocates Who Then Become Parents
Interest Area: Advocacy
Speaker: Leslie Seid Margolis

A Handbook on LRE Legal Rights
Interest Area: Inclusive Education
Speakers: Patricia Cox Waldman, Beth Wanger

Utilizing Arts Activities to Teach Disability Awareness
Interest Area: Inclusive Education
Speaker: Heather Downey

Inclusive Education in Malta: Ingredients & Training of Personnel
Interest Area: Multicultural/International Strand
Speakers: Elena Tanti-Burlow, Billie Nightingale, Ruth Falzon

Children and Youth with Disabilities as Victims of Crime
Interest Area: Criminal Justice Strand
Speaker: Patricia Sullivan

Self-Determination: Key to Smooth Transition from School to Community Employment
Interest Area: Transition Strand
Speaker: Linda McDowell

Customizing Community Supports to Maximize Individual and Family Control
Interest Area: Community Living
Speakers: Mark Mills, Judi Roun

Developing an Individualized Employer-Tested Approach to Job Development
Interest Area: Employment Strand
Speaker: Melinda Mast

Creating Integrated Daytime Opportunities
Interest Area: Employment Strand
Speakers: Pam Walker, Bonnie Shoultz

Bilingual Inclusion: Linking School Reform Efforts to Benefit All Students
Interest Area: Research
Speakers: Pam Hunt, Kevin Wooldridge, Maria Rosa Keys, Anne Hirose-Hatae, Sharon Strachan, Mallorie Baron, Pearl Wong, Procesa Gorrostieta

Comprehensive Transition Supports: Work, College, and "Spring Break"
Interest Area: Transition Strand
Speakers: Diane Browder, Tim Minarovic, Caroline Dipipi, Edward Grasso

Children in Inclusive Settings: Who Do They Play With At Recess?
Interest Area: Inclusive Education/Research
Speaker: Susann A. Terry-Gage

The Evolution of Parent Advocacy in Washington State
Interest Area: Advocacy
Speakers: Janet Adams, Carrie Masten, Sandy J. Silveria, Margaret-Lee Thompson

From Building a Behavioral Disorder Classroom to Building District Capacity
Interest Area: Positive Approaches
Speakers: Deborah Simak, Paul Malette

Friday,
December 4, 1998
11:45 AM– 2:00 PM

Sexuality: Issues & Challenges Facing People with Disabilities
Interest Area: Sexuality Strand
Speakers: Kathyrn O'Connell, Kate Corcoran

Victories & Challenges in Developing Housing for People with Disabilities
Interest Area: Community Living Strand
Speaker: Lynn Davison

Early Childhood Crackerbarrel
Interest Area: Early Childhood Strand
Facilitators: Beth Brennan, Elizabeth Erwin

Fetal Alcohol Syndrome: In Trouble With The Law
Interest Area: Advocacy
Speakers: Ann Streissguth, Barbara Wybrecht

Friday,
December 4, 1998
11:45-3:15 PM

Communities of Tomorrow: A Think Tank on Community Living
Interest Area: Community Living
Speakers: Jay Klein, Judith Snow, Joe Wykowski, Patti Scott, Lynda Baumgardner, Vicki Cammack and a cast of many others

Friday,
December 4, 1998
12:05-2:00 PM

Working to Scale in Urban Schools
Interest Area: Urban Issues Strand
Speaker: Elizabeth Kozleski

Friday,
December 4, 1998
1:00-2:00 PM

Stop Settling for Mediocrity
Interest Area: Advocacy
Speaker: Jeffrey L. Strully

"Whoever You Are": Using Children's Literature in Successful Inclusive Communities
Interest Area: Inclusive Education
Speakers: Mary Fitzgerald, Anne Wilson

Building Alliances: The Network Series for Community Team Development
Interest Area: Community Living
Speaker: Joyce Dean

Preparing Pre-service Teachers for Inclusive Teaching
Interest Area: Personnel Preparation/Higher Education Strand
Speaker: Linda Davern

Music for All: Strategies for Including Everyone in the Joys of Music Making
Interest Area: Creative/Performing Arts
Speakers: Mara Sapon-Shevin, Mayer Shevin

Critical Challenges to Self-Determination
Interest Area: Self-Determination
Speakers: Fredda Brown, Christopher Oliva, Carole Gothelf

Continued on page 24

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Linking Functional Assessment to the Instructional Process Guide

Functional Assessment Guide

This guide provides:

- A detailed process for conducting functional assessment
- Forms and supplementary materials to support this process
- Methods for organizing and reporting functional assessment information -- portfolios and narrative comprehensive reports (a sample report is included)

LRCONSULTING
P.O. Box 6049-747 • Katy, TX 77491-6049
(281) 395-4978 • Fax (713) 973-1271
http//www.lrconsulting.com

1:00-2:00 PM Continued from page 23

Social Support System for Persons with Disabilities in Today's Russia

Interest Area: Multicultural/International Strand
Speaker: Elena Iarskaia-Smirnova

What Teachers Really Think about Including Students with Severe Disabilities

Interest Area: Research
Speaker: Debra K Lynch

Fiesta Educativa

Interest Area: Multicultural/Inclusive Education
Speaker: Hector Mendez

International Inclusion: A South African Perspective

Interest Area: Inclusive Education/Multicultural
Speaker: Joya Carter

Interviewing Techniques That Are Successful in Obtaining Information from Persons with DD

Interest Area: Criminal Justice Strand
Speaker: Mary Hayden

Friday, December 4, 1998 1:00 -3:15 PM

The Dark Side of Benevolence: From Eugenics to Telethons and Back Again

Interest Area: Ethics and Rights
Speakers: Norman Kunc, Emma Van der Klift

The Transformative Power of Art

Interest Area: Creative and Performing Arts
Speakers: Pat Claytor, Rose Kelly

Caregiving Issues of Aging Parents of Adult Children with Autism

Interest Area: Family
Speakers: Anne Donnellan, Jean Hauser, Charles Hart

Structuring Staffing for Inclusive Schooling: Urban, Rural & Suburban Strategies

Interest Area: Inclusive Education
Speakers: Ann Halvorsen, Linda Lee, Mary Falvey, Dona Meinders, Deborah L. Tweit-Hull

Anger Management 101

Interest Area: Communication
Speaker: Linda Hertell

Simulations: Activities to Enhance the Skills of Facilitators

Interest Area: Communications
Speakers: Marilyn Chadwick, Carolyn Nuyens

Research to Practice for Preservice Teacher Training

Interest Area: Positive Approaches/Research
Speakers: Wayne Sailor, Rachel Freeman, Doug Anderson, Denise Poston

Employment Crackerbarrel on Policy & System Change Issues

Interest Area: Employment Strand
Facilitators: Christopher Button, Ian Pumpian, Joe Skiba, Nicholas J. Certo, Zeek Harris

Inclusion Roundtable

Interest Area: Inclusive Education
Speakers: Dorothy Kerzner Lipsky, Alan Gartner

Surviving Due Process Hell: Strategies for Support and Survival

Interest Area: Advocacy
Speakers: Gail M. McGregor, Lou Brown, Judy Gran

HR2020: ADAPT's Vision for the Future

Interest Area: Advocacy
Speakers: Jennifer Burnett, Bob Liston, Steve Verriden, Linda Anthony, Michael Auberger

Facilitating Inclusion Through Person Centered and Positive Behavioral Support Strategies

Interest Area: Positive Approaches
Speakers: Sara Woolf, Carol Schwager, Philippa Orszulak, Daniel B. Crimmins

Functional Behavioral Assessment: A School Based Assessment

Interest Area: Positive Approaches
Speakers: Suzanne M. Swindell, Sara Egorin-Hooper, Sally Barbieri

Friday, December 4, 1998 2:15 PM-3:15 PM

Portraits of Inclusive Schools in an Urban Setting

Interest Area: Urban Issues Strand
Speakers: Mary Ann Fitzgerald, Jane Glodoski

Preparing For Partnership: Preparing Pre-service Educators for Collaboration

Interest Area: Personnel Preparation/Higher Education Strand
Speakers: Amy C. Donnelly, Amy Kuhns Bartlinski

New View - Cultural Sensitivity "Hey, My Child Has a Disability"

Interest Area: Early Childhood
Speakers: Jean Ann Vogelman, Annette Frazier, Denise Taylor

Continued on page 25

2:15-3:15 PM Continued from page 24

Early Conversations from the "Union Hall"
Interest Area: Governmental Affairs
Speakers: Ryan Geake, Debbie Reid

Right Rules
Interest Area: Criminal Justice Strand
Speakers: Tom Verkler, Rob Wybrecht

Use of FM Systems with Children Who Are Deaf/Blind
Interest Area: Research
Speaker: Barbara Franklin

Including the Family: The Family-Centered Multidisciplinary Process
Interest Area: Early Childhood Strand
Speakers: Lisa Schneider, Eileen Keenan, Philippa H. Campbell

Self-Advocate Leadership for the 21st Century
Interest Area: Advocacy
Speakers: Mike Ward, Tia Nelis

Why Shouldn't We Be Friends?
Interest Area: Inclusive Education
Speakers: Wilson Buswell, Aaron Flint

A Self-Advocate's Story: One Man's Story of Confessing to a Crime He Did Not Commit
Interest Area: Criminal Justice Strand
Speaker: Russell Daniels

Peace Crackerbarrel
Interest Area: Spirituality Strand
Speaker: Alan Berger

Creating an Inclusive Accountability System: Colorado's Expanded Standards & Assessment Process
Interest Area: Inclusive Education
Speakers: Terri Rogers Connolly, Janet Filbin, Beth Schaffner

Guidelines for Systematic Preference Assessment: The Search for Meaningful Outcomes
Interest Area: Self-Determination
Speakers: Diane Browder, Fredda Brown

Surrogate Parents: IDEA's Safety Net for Children under Public Guardianship
Interest Area: Advocacy
Speakers: Lucille Zeph, Charles Zeph

— Friday Poster Sessions —

Friday
December 4, 1998
Poster Session III
9:00-11:00 AM

Welcoming All Children: The Philadelphia Inclusion Network
Interest Area: Inclusive Education
Speakers: Lillian M. McCuen, Suzanne Milbourne

Make It Clear: How to Translate Materials in Plain Language
Interest Area: Communication
Speakers: Janet Pringle, Evean Miller

Stakeholder Perspectives on the Challenging Behavior of Individuals with Disabilities
Interest Area: Research
Speaker: Mike Ruef

Individual Program Plan Differentials in Segregated and Integrated Work Programs
Interest Area: Employment and Careers
Speakers: Keith Storey, Michael Pendergast

Audiobooks to Promote Literacy Among People Who Cannot Read
Interest Area: Leisure and Recreation
Speakers: Margaret Stout, Paul Stout

Early Childhood Inclusive Programs: Everyone Welcome Here
Interest Area: Early Childhood
Speakers: Sandy Gregory, Helen Trivits, Carol Workman

Connections - The Power of Youth
Interest Area: Inclusive Education
Speakers: Dianne Campbell, Will Main, Erin Bily, Donna Daggett, Chris Biley, Sean Chausse

Friday
December 4, 1998
Poster Session IV
1:00-3:00 PM

The Tri-State Consortium on Positive Behavior Support
Interest Area: Positive Approaches
Speakers: Tim P. Knoster, Don Kincaid, Carol Schall, Jeannine Brinkley

Beyond the Mandatory Topics: Developing Staff for Community Inclusion
Interest Area: Personnel Preparation
Speakers: Michael McAllister, Rosa Landes-McAllister

Evaluating the Effect of Self-Determination Instruction on Student Self-Determination Ability
Interest Area: Self-Determination/Research
Speakers: Dalun Zhang, , Jane M. Everson

Meeting Different People on the Internet
Interest Area: Communication
Speakers: Shelley Trigg, Loraine Luterbach, Sandra Cormier

Demonstrating Research to Practice by Using Video Self-Modeling Interventions
Interest Area: Transition
Speakers: Kathy Ben, Marilyn Connor

Challenging Behavior: What Do You Do When Your Functional Assessment Results Are Unclear?
Interest Area: Positive Approaches
Speakers: Madonna Tucker

Circles of Support, Community Faciliators, a Life with Meaning. Does It Work?
Interest Area: Community Living Strand
Speakers: Sally Sehmsdorf

Creating the Ethical Organization
Interest Area: Ethics/Rights
Speakers: Kathleen Biersdorff, Gail Davis

Multi-Age Center-Based Classrooms: Inclusive Environments for All Learners
Interest Area: Inclusive Education
Speakers: Mary J. Foundopoulos, Susan Keetle

1998 TASH Conference Exhibits

The TASH Conference promises to be the place to host over 2,500 of your customers! Each exhibitor will receive three conference registrations, a complete booth package, TASH discounted hotel and airline rates, and the opportunity to capture an audience interested in the innovative services, products, and information available to assist people with disabilities from around the world.

Plan to join us in the Exhibit Hall for our Grand Opening Reception on Wednesday, December 2, 1998 from 5:00 PM to 7:00 PM.

The Exhibit Hall will be filled with exhibits of the products, publications and services TASH conference attendees are looking for. We welcome back many vendors familiar to our attendees and we are pleased to have many newcomers joining us in Seattle. Plan to do your holiday shopping with us!

This year we will hold drawings for door prizes, in the Exhibit Hall each day of the conference. In addition to the daily door prizes there will be a grand prize drawing for two round-trip airline tickets in the Exhibit Hall on Saturday, December 5th.

Some of the many exhibitors to be seen at the 1998 TASH conference include:

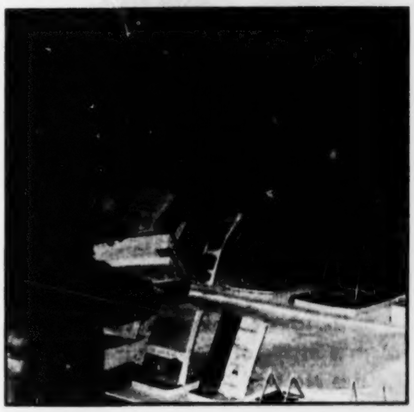
- Abingdon Press
- AFB Press/American Foundation for the Blind
- Aurora Ministries – Bible Alliance
- Bridge Ministries for Disability Concerns
- Brooks Publishing Company
- Diverse City Press
- Dorling Kindersley Family Learning
- DynaVox Systems (formerly Sentient Systems Technology)
- Inclusion Press/Marsha Forest and Jack Pearpoint
- Institute on Disability/UAP
- International Rett Syndrome Assn.
- Laureate Learning Systems, Inc.,
- Lifestyle Enhancement Service
- Magic Wand Solutions
- Marian Management
- National Professional Resources, Inc
- Peak Parent Center
- School of Social Work – Eastern Washington University
- Singular Publishing Group, Inc.
- The Council on Quality and Leadership
- United Cerebral Palsy Association of King and Snohmish Counties
- University of San Francisco
- Visions for Independent Living

Added Exhibit features to maximize traffic in the Exhibit Hall:

- Complimentary coffee for exhibitors in the exhibitor lounge.
- Food service in the Exhibit Hall, with ample space for attendees to browse while enjoying breakfast or lunch.
- Conference Registration and Information areas located near the Exhibit Hall.
- The opportunity to receive a free set of mailing labels of conference attendees.
- Visual and Performing Art displays held in the Exhibit Hall throughout the conference.

Exhibit Schedule

- Exhibit Set Up: Wednesday, December 2, 1998, 12:00 PM - 5:00 PM
- Opening Reception: Wednesday, December 2, 1998, 5:00 PM - 7:00 PM
- Exhibit Hours: Thursday, December 3, 1998, 7:30 AM - 3:00 PM
- Friday, December 4, 1998, 7:30 AM - 3:00 PM
- Saturday, December 5, 1998, 7:30 AM - 12:00 PM
- Exhibit Breakdown: Saturday, December 5, 1998, 12:00 PM - 5:00 PM



To obtain an application or for more information contact Rose Holsey at 800-828-8274 ext. 100, e-mail: rholsey@tash.org

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Be Seen at the TASH Media Festival!

Do you have a fantastic video that you'd like to market to the TASH audience? A video that depicts inclusive lives and experiences of people with disabilities; instructs parents or professionals who support people with disabilities; demonstrates school and community inclusion; or addresses specific training needs or current issues? If so, now is the time to take advantage of the opportunity to show your video to over 2,500 TASH conference attendees.

The TASH conference attracts an incredibly diverse group of people with disabilities, parents, advocates, administrators, educators, professional, and community members who are all concerned with rights, equity, and full participation in the lives of people with disabilities.

For only $149.00 per video, we will show your film in the TASH Media Festival, ***and*** give you a 1/4 page ad in the conference program ***free***.

VOLUNTEER ALERT!

With the TASH annual conference just around the corner, it's time to once again call upon the dedicated individuals who work so diligently to help us keep the conference organized and running smoothly.

• • •

Your services are urgently needed!

• • •

Whether you've participated as a volunteer before, or would like to do so for the first time, we welcome your assistance.

If you would like to attend the conference and save on registration fees, this is the deal for you! Volunteers donate a minimum of 10 hours of service during the conference in exchange for complimentary registration to attend conference sessions during your non-volunteer periods.

If you are interested, please contact
Priscilla Newton at 1-800-482-8274, ext. 102
or e-mail: pnewton@tash.org

Not Able to Exhibit This Year?

You can still reach the TASH Audience!

If you are unable to have a booth in the TASH exhibit hall this year, but would like to take advantage of the opportunity to have your books, videos, brochures, catalogs, or pamphlets distributed or displayed to TASH Conference attendees, then this offer is for you!

Brochures announcing new publications, videotapes, conferences and workshops, or books which are targeted to parents, advocates, professionals, educators, community service providers, or anyone attending the conference are welcome.
For $119.00 we will display your product in the exhibit show!

If you would like an application to be part of the Display Table, please contact the TASH Central Office at 1-800-482-8274.

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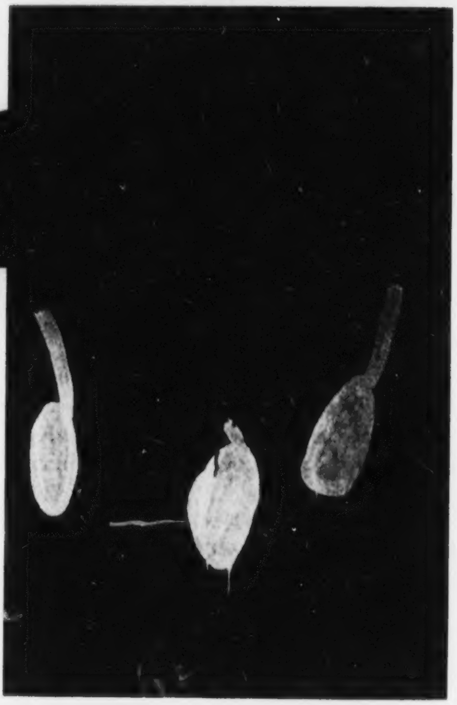
Art Show & Performing Arts in the Exhibit Hall

NEW THIS YEAR!



Title: "Herons"

ARTIST: MARLON MULLEN

About the Artist: Marlon has been described as a "painter's painter." His images are semi-abstract and eclectic. Marlon exhibits his work through the National Institute of Art and Disabilities (NIAD). To contact NIAD, call 510-620-0290 or visit their web site at http://thecity.sfsu.edu/~niad

This year's conference committee is encouraging an art display and a schedule of performances in the TASH Exhibit Hall to celebrate the contribution that people with disabilities have made to their communities through arts and entertainment. Whether your interest is in art, music, dance or drama, you are invited to participate in this show.

Artists are encouraged to display a sampling of their work in the art show, which will be open during the hours of the exhibit hall. (see page 26 for specific times). A biography of each participating artist will be listed in the conference program.

Performing Artists will have the opportunity to perform on stage in the exhibit hall at a pre-scheduled time during the designated show times each day. The stage will be located adjacent to the art show and the food service area. Participants will have the opportunity to eat lunch or a snack while enjoying the performances. A specific schedule of performances will be listed in the official conference program.

For information on participating in the show, call Denise Marshall at 1-800-482-8274 x103 or email dmarsh@tash.org.

Saturday, December 5, 1998
8:00 -9:00 AM

The Many Things an Advocate Must Do Today to Bring About True Advocacy
Interest Area: Advocay
Speakers: Roy Brown, Joe Sebenick

Developing Effective Inclusive Practices: What The Experts Are Saying.
Interest Area: Inclusive Education
Speakers : Lewis Jackson, Felix Billingsley, Diane Ryndak

Video Documents - Breaking Down the Barriers Created by Words
Interest Area: Self-Determination
Speakers: Ryan Geake, Debbie Reid

Supporting Young Children with Disabilities in Community-Based Programs
Interest Area: Early Childhood Strand
Speakers: John Filler, Janet Butz, Catherine Lyons, Jeffery Gelfer, Cynthia Lau

Teaming for Literacy Development: It's Everybody's Job!
Interest Area: Inclusive Education
Speakers: Susan Keetle, Mary J. Foundopoulos

The Road Traveled
Interest Area: Inclusive Education
Speakers: Jane Glodoski, Jessie Vance, Marcus Loppnow, Brenda Boggs, Tracy Carus

Free and Appropriate: Monitoring, Accountability, and IDEA
Interest Area: Inclusive Education
Speakers: Diane Lipton, Mike Remus, Kathleen Gee, Alan Coulter

Across the Lifespan: Case Studies of Social Integration
Interest Area: Community Living
Speaker: Zana Marie Lutfiyya

The Power of Teaching
Interest Area: Higher Education
Speaker: Freddie Vaughns

Are We Listening? Three Perspectives on Transition: Professionals, Parents, and Young Adults
Interest Area: Transition Strand
Speaker: Bud Cooney

Continued on page 29

8:00-9:00 AM Continued from page 28

"She'll Only Use It To Get Her Own Way"

Interest Area: Communication
Speaker: Trevor McDonald

Family & Service Coordinator Perceptions of Outcomes from the IFSP

Interest Area: Early Childhood/Research
Speakers: Lee Byoung-In, Eunhee Paik

From the Cradle to the Grave

Interest Area: Criminal Justice Strand
Speaker: Jeri Houchins

An Institution is Not a Home: Lessons Learned

Interest Area: Advocacy
Speakers: Kate Blisard, Mary Kay Weber, Jeffrey Bruce, Bernard King

Whole Brain Learning: Inclusive Academics, Music & Games

Interest Area: Inclusive Education
Speaker: Robin Smith

Preserving Respite Care As A Valued Support for Families

Interest Area: Family
Speakers: Jeff Bassin, Colleen Willis, Maggie Edgar

Forging New Roles in Transition for Parents of Young Adults

Interest Area: Tranistion Strand
Speakers: Don McDermott, Toni McDermott, Ron Broome, Kathy Broome

Lifelong Inclusion in an Urban Setting

Interest Area: Inclusive Education
Speakers: Janice Payne, Linda E. Rosenthal, Walter Thies, Charles Fitzgerald

Merging Reform Efforts: Accountability for the Learning of All Students

Interest Area: Inclusive Education
Speakers: Beth Schaffner, Joan E. Rademacher, Linda Montoya, Janet Filbin

A Child with a Learning Disability Becomes a University Professor

Interest Area: Self-Determination
Speaker: Dayle A. Upham

Music Time: The Perfect Inclusion Tool

Interest Area: Related Services
Speaker: Wendy Zieve

Person-Centered Planning: Much More Than Planning!

Interest Area: Self-Determination
Speaker: Rick Tutt

Valuing All Abilities: Putting the Heart in Inclusion

Interest Area: Positive Approaches
Speakers: Karen Larsen, Thom Worlund, Edi Purvis

Broadening School-Based Support Teams

Interest Area: Inclusive Education
Speakers: Nadine Lada, Nancy Hurley

The Police Interrogation Room

Interest Area: Criminal Justice Strand
Speaker: Robert A. Perske

Saturday, December 5, 1998 8:00 -10:15 AM

Translating Therapy Into Family/Counseling Life

Interest Area: Early Childhood
Speaker: John Murray

Yearning for Community: Families, Friends and Partners Reflect on Life-Sharing

Interest Area: Community Living Strand
Speaker: David Wetherow

Special Education: Systems Change from the Legal Perspective

Interest Area: Advocacy
Speakers: Leslie Seid Margolis, Eileen Ordover

The Sexual Knowledge, Attitude & Feelings of People with Developmental Disabilities Staff & Families in Austria

Interest Area: Sexuality Strand
Speakers: Wolfgang Plaute, Ilse Polleichtner, Antonia Schlick

Saturday, December 5, 1998 9:15 -10:15 AM

Creating a Brighter Future Through Individual-Driven Supported Employment

Interest Area: Employment Strand
Speaker: Laura Owens-Johnson

Supporting Inclusive Practices via a Statewide Peer to Peer Network

Interest Area: Inclusive Education
Speakers: de Vergne Goodall, William R. Sharpton, Margaret Coady, Margaret Lang

Creating Inclusion: One Child's Adventures in Community Living

Interest Area: Positive Approaches
Speakers: Thomas Robingon, Sharon Taylor

It's My Life: Preference-Based Planning for Self-Directed Goal Meetings

Interest Area: Self-Determination
Speaker: Emilee Curtis

Creating Responsive Services: Family Perspective on Organizational Support

Interest Area: Research
Speakers: Susan O'Connor, Kathleen Hulgin

Organizing Parents for Systems Change

Interest Area: Advocacy
Speakers: Robert G. Mochan, Claire Hoffman, Joyce Moss, Jennifer Ashley, Ginny Conway

Spirituality and Leadership: Implications for Inclusive Schooling

Interest Area: Spirituality
Speaker: Maureen Keyes

"What Works?": Effective School-Wide Behavior Support Practices

Interest Area: Positive Approaches
Speakers: Pat Mirenda, Catherine Remedios, William McKee

Building Partnerships to Include All Children in Child Care

Interest Area: Early Childhood Strand
Speakers: Marilyn S. Dunning, Karen Martin

Meeting the Needs of Students Who Severely Challenge High Schools

Interest Area: Students Who Severely Challenge Schools
Speakers: Mary Jane Rapport, David Riggs, Andrew Wilson

Transforming Regular and Special Education: High Standards for All

Interest Area: Inclusive Education
Speakers: Maria Timberlake, Betsy Enright

Individual and Sound-field FM Amplification: Managing "Listening" in Inclusive Settings

Interest Area: Related Services
Speakers: Robert Flexer, Lynn Frateschi, Carol Flexer

Continued on page 30

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9:15-10:15 AM Continued from page 29

Brothers, Friends, and Colleagues: Working Together as Advocates
Interest: Advocacy
Speakers: Joe Meadours, James Meadours

Killing the Autism with Kindness and Cool Talk!
Interest Area: Self-Determination
Speakers: Rosa Landes-McAllister, Patricia Creazzo, Patricia Ann Fernandez, Mary Lapos, Kendall Seybert, Jennifer Paige Seybert, James Seybert

From Institutions to Inclusion - A Roadmap for Success
Interest Area: Management Issues
Speakers: Max Chmura, Marti Romero-Mitchell, Patty Veselsky

Making a Difference: Initiating Family Centered Care in the Nursery
Interest Area: Family
Speakers: Tracey Finch, Maureen Godwin, Nancy Reese, Kerry Hodgkinson, Joanie Vanderpol

Creating Futures Together: Using Participatory Action to Transform Services
Interest Area: Transition Strand
Speakers: Deborah A. Gilmer, Janet May,Elizabeth DePoy, Ann Hatmann

Issues in Assessment, The Death Penalty & Mental Retardation
Interest Area: Criminal Justice Strand:
Speakers: William Edwards, Jennifer Johnston, Denis Keyes, Caroline Everington

Saturday, December 5, 1998 9:15 -11:30 AM

Advocates and Allies
Interest Area: Criminal Justice Strand
Speakers: Diane Bryen, Lisa Sonneborn, Sharon Potter, Ray Gagne

Alexander's...Very Bad Day: A Positive Supports Approach
Interest Area: Positive Approaches
Speaker: Paul Selby

Working Together for Better Solutions
Interest Area: Positive Approaches
Speaker: Julie Shryock

The Challenge of Person Centeredness
Interest Area: Positive Approaches
Speakers: Patricia Fratangelo, Michael Kendrick

Transition Services and Best Practices: A Five Year Study
Interest Area: Transition Strand
Speakers: Rachel McMahan, Joan Mazzoli, Robert Baer, Lawrence Dennis

Employment Multiculturalism in the New Century
Interst Area: Employment
Speakers: Vener Azurin, Teresa Cronin, Susan Prout

Challenging Behaviors: Positive Solutions - Contextualizing Positive Behavior Support
Interest Area: Positive Approaches
Speaker: Tim P. Knoster

Saturday, December 5, 1998 9:15 -12:45 PM

Stop the Hurting: Positive Supports for People with Autism
Interest Area: Community Living
Speakers: Jeffrey L. Strully, Charlotte Mazzeo-Comeione, Jennifer Lengyel, Cindy Strully

Saturday, December 5, 1998 10:30 -11:30 AM

Children and Youth with Disabilities as Perpetrators
Interest Area: Criminal Justice Strand
Speaker: Patricia Sullivan

Internal Control Psychology: Relationships, Self-Determination and Special Education
Interest Area: Positive Approaches
Speakers: David Sansone, Patric Barbieri, Trish Costa

Adapting The World to Meet Your Needs
Interest Area: Employment Strand
Speaker: Laura Owens-Johnson

Parents & Professionals: How Do We Communicate and Advocate Together?
Interest Area: Family
Speakers: Nancy Algert, Brooke Durbin, Kathy May, Alison Strand

Transition from School to Career: A Success Story
Interest Area: Transition Strand
Speakers: Carole Isakson, Todd Stabelfeldt, Sheryl Burgstahler

The Deaf-Blind Community
Interest Area: Deaf Culture
Speakers: Donna Miles, Jelica Nucclo

Unexpected Benefits of High School Peer Tutoring
Interest Area: Inclusive Education
Speakers: Amy Wildman Longwill, Phil Wilson, Harold L. Kleinert

The People First International Conference: Tools from the U.N. & Our Quality of Life Survey
Interest Area: Advocacy/Research
Speakers: Beverly Tallman, Kristin Ryan, Joseph Pichler

Self-Determination: Management of Personal Lifestyles by Individuals with Extensive Needs
Interest Area: Self-Determination
Speakers: Scott Arnett, David Lovett, Laura Bixler, Kathryn Haring

Gays & Lesbians with Disabilities Talk to the "Organized" Gay Community
Interest Area: Sexuality Strand
Speakers: Ann Heler, Lee Lightning, Shawna, Bonnie Shoultz

Positive Peer Pressure: Using Peers to Assist Students with Special Needs
Interest Area: Inclusive Education
Speakers: Janice Siebenhaar, Cynthia Walker, Carolyn Auld

Creating Inclusive Dance Classes for Children with Disabilities
Interest Area: Creating/Performing Arts
Speakers: Robin Greenfield, Melinda Lindsey, Ellen Hunt-Landry

How An Emerging Theory of Development Can Inform Positive Supports
Interest Area: Positive Approaches
Speakers: Lucille Zeph, Alan Kurtz

Building the Bridges Between Communication and Positive Behavioral Change
Interest Area: Positive Approaches
Speaker: Christine Cox

Envisioning A Future For Your Family
Interest Area: Early Childhood Strand
Speakers: Jean Ann Vogelman, Annette Frazier, Denise Taylor

Continued on page 31

10:30-11:30 AM Continued from page 30

Saturday, December 5, 1998 10:30 -12:45 PM

Supporting Students with Autism at the District and School Level
Interest Area: Inclusive Education
Speakers: Vicki Rothstein, Catherine Remedios, Paul Malette, Christine Brodie, Allen Stevens

Creating Community-based Housing Options in Washington State
Interest Area: Community Living Strand
Speakers: Jan Navarre, Gil Roos, Forest Wetzel, Brigett Helsten, Rene Roos, Diane McCalmon

An Inclusive Adult Day Care Model
Interest Area: Aging
Speakers: Holly Menzie, Mary McMurray, Patricia A. Colombo

Ensuring a Family Voice in Inclusive School Improvement Efforts
Interest Area: Inclusive Education
Speakers: Beth Schaffner, Janet Filbin, Robin Brewer, Romie Tobin

Building Linkages between Assessment & Instruction: Outcomes-Oriented Strategies
Interest Area: Inclusive Education
Speakers: Jan Writer, Terry Murphy

Over Representation: Problem or Symptom?
Interest Area: Governmental Affairs
Speakers: Dorothy Kerzner-Lipsky, Alan Gartner

Saturday, December 5, 1998 11:45 -12:45 PM

Self-Determination for Individuals with Cognitive Disabilities in Alternative Community Programs
Interest Area: Self-Determination
Speakers: Lori Noto, Robert McCaffrey, Justin Bruckie, Suki Incillo

Community-Based Instruction in Neighborhood Schools
Interest Area: Inclusive Education
Speakers: Jane Scarffe, Vickie Andrews

Delivering the Information So It Works
Interest Area: Positive Approaches
Speaker: Larry Douglass

One of Us
Interest Area: Family
Speaker: Nancy Rosenau

Using Project-Based Instruction to Ensure Active and Meaningful Participation
Interest Area: Inclusive Education
Speakers: Karen Waterbury, Jane Glodoski, Kendra Paar, Mona Mehra

Inclusive Education & Standard Based Reform: Developing Schools as Caring Communities for ALL
Interest Area: Inclusive Education
Speakers: Marquita Grenot-Scheyer, Kristin Geenen

"I Guess Like Sometimes I'm in the Dark": Teachers/Paraprofessionals Unprepared for Inclusion
Interest Area: Inclusive Education
Speakers: Susan M. Hamre-Nietupski, Ann McKee

Without "Vision" You are "Blind" to Opportunity
Interest Area: Self-Determination
Speaker: Kathleen Urschel

Enhancing Inclusion & Self-Determination: Teaching Students to Include Themselves
Interest Area: Inclusive Education/Research
Speakers: Martin Agran, Carolyn Hughes, Michael Wehmeyer

Florida Changes!! An Update on State Efforts for Systemic Change Supporting Inclusion
Interest Area: Inclusive Education
Speakers: Diane Ryndak, Denise Clark, Donna Gilles, Terri Ward, Michelle Polland

The Role of the Family Advisor in Supporting Parents in Obtaining Inclusive Education
Interest Area: Inclusive Education
Speakers: Judith Terle, Selene Almazan

"Start with the Arts" in Early Childhood Education
Interest Area: Early Childhood Strand
Speaker: Bonnie Bernau

Personal Safety Training for Persons w/DD & Facilitation of Healthy Social Relationships
Interest Area: Positive Approaches
Speakers: Stacey Hoffman, Susan Whaley

Inclusive Education Scheduling - Friend or Enemy?
Interest Area: Inclusive Educaiton
Speakers: Joanne Suomi, Michele Ziegler

Fetal Alcohol Syndrome Cradle to Grave: What It Is, Why It Hurts
Interest Area: Criminal Justice Strand
Speaker: Ann Streissguth

Sexual Orientation Interest and Action Group
Interest Area: Sexuality Strand
Facilitator: Ann Heler

Developing Transdisciplinary Teams in Rural Areas
Interest Area: Related Services
Speakers: Robin Greenfield, Jeff Brockett, Jane Coe-Smith, Gail Brown, Kathryn Welsh

Effective Transitional Planning: The Journey from Career Awareness to an Initial Career
Interest Area: Tranistion Strand
Speakers: Lynn Frateschi, Mary Wideman-Blake

Embracing Disability: The Spiritual Side
Interest Area: Spirituality
Speaker: Kathyrn O'Connell

The Criminal Justice System as a Level of Intervention for Students with Disabilities
Interest Area: Advocacy
Speakers: Barbara Ransom

Parents Guide to Mental Health and Community Connectors
Interest Area: Family

World Peace Through TASH

This year we will catch up from last year, decide on direct action TASH can take to promote World Peace, and spend some time being peaceful ourselves. Please join the Peace Interest and Action Group as we continue our 5th year of promoting peace.

Date: 12/4/98 Time: 2:15-3:15 Facilitator: Alan Berger

TASH Child Care Registration Form

Please fill out this form and return to TASH at the address listed below, NO LATER THAN 11/15/98. *MAKE CHECKS PAYABLE TO TASH.* A confirmation letter with release forms and a history/information form will be sent to you once payment is received. Please indicate the age each child will be on December 1, 1998.

CHILD'S NAME____________________ AGE:_____ SEX:____ BIRTHDATE:__________
CHILD'S NAME____________________ AGE:_____ SEX:____ BIRTHDATE:__________
CHILD'S NAME____________________ AGE:_____ SEX:____ BIRTHDATE:__________

Rates are $2.00 per hour per child with a consecutive three hour minimum period required.

Day	Hours of Operation	Specific Hours of Care Requested	Number of Children	TOTAL Per Day
Wednesday 12/2/98	8:00-4:30			$
Thursday 12/3/98	7:45-5:45			$
Friday 12/4/98	7:45-5:45			$
Saturday 12/5/98	7:45-2:30			$
		Non-Refundable Reg. Fee $5.00		$
		GRAND TOTAL		$

*Payment: *Check___ Visa___ Mastercard___ Discover___*

*Card#*______________________________ *Exp. Date*__________

The Child(ren) named above will be released ONLY to the person(s) signing this application and the following additional person(s):

Father/Guardian Full Name:____________________ Signature:_______________
Mother/Guardian Full Name:____________________ Signature:_______________
Address:_______________ City:____________ State:_______ Zip:_______
Home Phone#:_______________ Daytime Phone#:____________________

Mail this completed Registration Form and FULL PAYMENT payable in U.S. Funds
NO LATER THAN 11/15/98 to TASH 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204.

For Office Use Only
Amt. Recvd.____ Amt. Due____ On Timeline____ In Comp.____

Creating Futures Together

TASH Conference '98

SEATTLE, WASHINGTON

1998 TASH
Conference Registration Form
Creating Futures Together

Seattle, December 2-5, 1998

Mail form to: TASH
29 W. Susquehanna Avenue, Suite 210, Baltimore MD 21204-5201
Fax form to: 410-828-6706
Questions? Call 1-800-482-TASH

The registration form can also be found at our Web site at www.tash.org
You may use this form to register for the conference, become a TASH Member, or both!

Please Print

First Name________________ Last Name________________

Preferred Badge Name________________

Agency/School/University________________

Mailing Address________________

City/State/Province________________ Zip/Postal Code________________ Country________________

This address is: ☐ home ☐ work ☐ school ☐ other________________

Billing address (if different from above)________________

Agency/School/University________________

Mailing Address________________

City/State/Province________________ Zip/Postal Code________________ Country________________

Daytime Telephone________________ Work Telephone________________ Fax________________ e-mail________________

This address is: ☐ home ☐ work ☐ school ☐ other________________

Please circle the appropriate numbers that describe your affiliation (not more than 3):

1. Administrator/Adult Services
2. Administrator/Education
3. Administrator/Other
4. Adult Service Provider/Staff
5. Early Childhood Services
6. Government Personnel
7. Legal Services Provider
8. OT/PT
9. Parent/Family Member
10. Professional/Public Policy Advocate
11. Professor/Instructor (College/University)
12. Psychologist
13. Regular Education Teacher/Admin.
14. Related Services Provider
15. Self-Advocate
16. Social Worker
17. Speech/Language Pathologist
18. Special Ed. Teacher/Support Spec.
19. Staff Development/Trainer
20. Student
21. Supported Employment/Day Personnel
22. Other________________

Please fill out this section only if you are registering for the conference:

TASH Membership: I am a current member ☐ Individual ☐ Agency

Membership#________________

If you are a student member, please list your Student ID#________________

☐ I am becoming a member now *(please be sure to enter the applicable cost on the reverse side)*

☐ I am renewing my membership now *(please be sure to enter the applicable cost on the reverse side)*

Optional Conference Information Requested (please request by October 16, 1998)

☐ Accessibility Details

☐ Sign Language Interpreter

☐ Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited and there is a nominal fee.)

☐ Roommate Referral Program

☐ List any accommodation needs________________

Application for CEU credits have been made to the following organizations:

National Association of Social Workers, American Physical Therapy Association, The American Occupational Therapy Foundation, American Therapeutic Recreation Association and local education agencies.

☐ *I would like to request further information on CEU credits List Type*________________

To Become a TASH Member or Renew your Membership NOW. . .

You may also use this form to become a member at the same time you register for the TASH conference! This allows you to register for the conference at the reduced TASH member rate (see other side for member registration rates) or, *use this form to join as a member without registering for the conference.*

Membership rates are listed below. Determine the appropriate membership category, be sure to fill in the applicable rate on the reverse side of this form when entering payment information, and include payment at the time you submit your conference registration payment.

General International Membership (individuals)	$88.00
Agency/Business/University International Membership	$ 200.00
Self-Advocate, Parent, Full-Time Student	$45.00
Family International Membership (2 People)	$136.00
Lifetime International Membership	$1,000.00

(Add $10.00 to memberships in Canada and $25.00 to memberships outside of the U.S. and Canada to cover additional postage costs.)

Fill in appropriate membership rate on Line 8 on reverse side of this form.

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CONFERENCE REGISTRATION FORM

1998 TASH Conference - Creating Futures Together
December 2-5

Registration Rates 1998 Conference	**Current or Joining International Member**	**Non-Member**	**Please Enter Applicable Cost**
General	$199	$305	
Student/Paraprofessional/Parent (Professional)	$135	$229	
Self Advocate/Parent (non-professional)	$ 49	$ 79	
One Day Only Thurs Fri Sat	$ 99	$129	

1. Cost of Conference Registration from above .... 1. ________

2. Subtract Discount if applicable. **(Note: Only one discount can be applied.)**

   a. Subtract $20 per registration for groups of 5 or more registering for the full conference (all registrations must be mailed in the same envelope) .... 2a. ________

   b. Subtract $50 per full conference registration for a regular education teacher registering with a special education teacher, a paraprofessional, or related services personnel; or for any support staff person registering with a self-advocate (must be mailed in the same envelope). Indicate name of person with whom you are registering:
   ____________ .... 2b. ________

3. Add $40 late fee if you are registering after November 13th. After November 13th, all registrations will be on-site .... 3. ________

TOTAL Conference Registration Fee .... 4 ________

TASH Techs:

TASH Members	$65	1st Choice TASH Tech # ________
Non-Members	$80	2nd Choice TASH Tech # ________
Self-Advocate/Parent	$40	

Note: There is no charge for the Chapter Leadership TASH Tech.

5. Add Cost of TASH Tech (full day pre-conference workshops; see descriptions, page 7) .... 5. ________

6. Add $85 to attend the Special Pre-Conference Symposium on Dual Diagnosis .... 6. ________

7. TOURS
   a. Add $42.00 for the Grapes & Hops Tour (see description on page 3) .... 7a. ________
   b. Add $28 for the Seattle City Tour (see description on page 3) .... 7b. ________

8. Add TASH Membership Dues if you are joining TASH International or renewing with this application (see rates on front page of this form) .... 8. ________

9. Add $15 to also join your TASH Chapter (only applicable if you are joining or renewing membership for TASH International now) .... 9. ________

10. Yes, I will add $5 to support a self-advocate to attend the conference .... 10. ________

TOTAL Enclosed (Lines 4-10) .... ________

Payment Terms **TASH Federal ID#:51-0160220**

Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from cancellations received before November 6, 1998, and added to purchase orders not paid within 30 days after the conference. No refunds will be given for cancellations after November 6, 1998. A $15.00 fee for returned checks or unauthorized charges will be assessed.

Check enclosed Purchase Order/State Voucher No. ____________

Visa Mastercard Discover Card Number ____________ Exp. Date ________

Signature ____________

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1998 Conference Proposal Reviewers

Many thanks to the following people who spent countless hours reviewing the proposals submitted for this year's conference. We appreciate your time and knowledge, and truly could not accomplish such a mammoth task without you!

Richard Amado
Mary Anketell
Cathy Apfel
Lynda Baumgardner
Diane Baumgart
Alan Berger
Beth Brennan
Fredda Brown
Cynthia Burkhour
Barbara Buswell
Michael Callahan
Donald Cardinal
Josephine Chappell
Brian Cox
Dan Dotson
Susan Dotson
June Downing
Barbara Dyer
Elizabeth Erwin
Douglas Fisher
Katherine Fox
Deborah Gilmer
Darlene Hanson
Norris Haring
Angie Hawkins
Elisabeth Healey
Ann Heler
Linda Heyne
Robert Holland
Tim Knoster
Debra Kunz
Valerie Lava
Donna Lehr
Ming-Gon Lian
Barbara Ludlow
David Mank
Nancy Meltzer
Patricia Mueller
Anna Lou Pickett
Beverly Rainforth
Linda Rammler
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Marcie Roth
Diane Ryndak
Caren Sax
Patti Scott
Mayer Shevin
Bonnie Shoultz
Judith Snow
Charlotte Spinkston
Fred Spooner
Julie Stone
Wally Szyndler
Darlene Talavera
Jerry Whitworth
Pamela Wolfe
Gail Zahn
Nancy Zollers

1998 Local Committee

Our thanks also to the following for providing invaluable information about the local area, for recruiting local presenters and volunteers, testing the tours, and most importantly for showing such enthusiasm and spirit, both of which will help ensure a dynamic and lively conference. Thank you!

Susan Atkins
Colleen Blakely
Dennis Campbell
Carolyn Carlson
Shan Shan Chien
Cindy Christianson
Kathy Collman
Duane Davis
Steve Elliott
Cathy Fromme
Jenny Grant
Michelle Grant
Norris Haring
Jackie Henderson
Monique Hernandez
Vicki Isett
Sharon Jodock-King
Alan Jodock-King
Jerry Kessinger
Carrie Masten
Ken Miller
Shirley Milliren
Cheryl Monk
Jan Navarre
Joanne Preston
Leah Preston
Kim Preston
Melanie Richardson
Lois Rogers
Mike Rogers
Lyle Romer
Mary Romer
Kasaundra Salinas
Susie Schaefer
Megan Seeyle
Sally Sehmsdorf
Margaret-Lee Thompson
Pam Wilson
Laura Wood
Margy Woodward
Joseph Wykowski

1998 National Conference Committee

Carol Berrigan
Douglas Biklen
Beth Brennan
Lou Brown
Barbara Buswell
Mark Doyle
Marcie Goldstein
Norris Haring
Elisabeth Healey
Donna Lehr
Tia Nelis
Elizabeth Obermayer
Linda Rammler
Mary Romer
Susie Schaefer
Mary Stauffer
Joseph Wykowski
Lucille Zeph
Nancy Zollers

Thank you to the above committee members who were active in shaping this year's conference. TASH members who have recently joined the commiteee or are interested in joining the committee for the 1999 Conference will receive information about future committee meetings. Any questions should be directed to Denise Marshall, 410-828-8274 x103 or dmarsh@tash.org

A letter to TASH members from Deborah Martin West about our friend and colleague, Lee West:

On October 7, 1997 Lee West, the President of the Louisiana (LA) TASH South and a long-time member of International TASH, passed away. While visiting friends in his home state of Tennessee, Lee died quietly in his sleep from a heart condition. He was 41. Lee gave many years of heartfelt service to TASH and to persons with disabilities throughout his career.

Lee was my husband, my colleague and my best friend. He loved his work and was a passionate advocate. He worked tirelessly to advocate for state-of-the-art services for those he served. Only fifteen short years ago, he introduced me to my very first TASH conference in Chicago, eager to ensure that I saw all the "musts" like Lou, Ian, Mary and Gary, to name a few. It wasn't long before everybody knew Lee. He was not shy about expressing his views on how to improve each TASH conference, and he attended every board meeting to be sure he would be heard. He always said that going to the TASH conference every year helped him confirm that he wasn't the only person who believed in the progressive techniques he promoted at home in New Orleans.

Over the years, he accomplished much to be proud of. He started one of the first supported employment agencies in our state, worked under a grant that introduced community based programming in the New Orleans area school systems that still exists today, wrote millions of dollars of grants to assist in obtaining progressive services, and co-founded the largest case management agency in the state of Louisiana.

One accomplishment he was especially proud of occurred just one short year before his death. For almost a decade, Lee lobbied to bring the national conference to the city he loved most and called home, New Orleans. He lived to see that happen and it made him very happy. I know that he will be missed by all who knew him at TASH.

At his funeral, the priest said that when you die, all of the good things you have done on this earth will be waiting for you with God. Surely, Lee was met by his lifetime of advocacy and love. Your prayers for him will be deeply appreciated.

Deborah Martin West
July 14, 1998

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— REALIZE THE DREAM —

A Day To End Special Segregation

Sunday, October 11, 1998 in Washington, DC
1:00-4:00 PM
The Ellipse (between the White House and the Washington Monument)

The M.A.I.N. Event

(Sponsored by MAIN - Mighty Alliance for Independence Now)
(A Project of TASH)

Make your plans now to gather in Washington D.C.on Sunday, October 11, 1998 with thousands of children, parents, teachers, administrators, and disability advocates to call for equality of opportunity for children with disabilities.

In 1954, the Supreme Court Decision in Brown v. Board of Education stated that:

> ***"We come then to the question presented: Does segregation of children in public schools solely on the basis of race, even though the physical facilities and other "tangible" factors may be equal, deprive the children of the minority group of equal educational opportunities? We believe that it does...We conclude that in the field of public education the doctrine of 'separate but equal' has no place. Separate educational facilities are inherently unequal. Therefore, we hold that the plaintiffs and others similarly situated for whom the actions have been brought are, by reason of the segregation complained of, deprived of the equal protection of the laws guaranteed by the Fourteenth Amendment." ****
>
> *US Supreme Court Decision as presented by Chief Justice Earl Warren on May 17, 1954.*

In spite of the fact that the Supreme Court ruled against 'separate but equal' in 1954, it was not until advocates on behalf of African American children pushed the issue, that the discriminatory practice of forced segregation ended.

The Individuals with Disabilities Education Act (IDEA), passed nearly 25 years ago, promised children with disabilities that, from that day forward, they would be recognized, appreciated, and educated as full participating, young Americans whose right to life, liberty, and the pursuit of happiness would be afforded them, regardless of the nature of their disability. America has not kept its promise to children. America has not made IDEA the law of the land. If every child is to grow up to be truly free, IDEA must be implemented in every school district, every school house, every classroom in this country! IDEA can work!

As a Civil Rights issue, MAIN sees this 'special segregation' as just as important to families of children with disabilities as school desegregation was to African American families in the 1960s.

Join us for a day of awareness in the heart of American democracy. Guest speakers will include national policymakers, disability and children's advocates, educators, entertainers and sports personalities.

Spread the news of this event far and wide. Share it with family members, friends, neighbors, your PTA, your teachers, and your elected representatives. Bring your friends, big and small, and join us!

For additional information or to be added to our event update list, e-mail IDEArally@tash.org, call 1-800-482-8274, or check out our website at www.tash.org.

About M A I N

Mighty Alliance for Independence Now is a group of individuals (advocates, activists, parents, and adults with disabilities) who have long recognized, both individually and collectively, that a solid advocacy body must exist that defends and advances the concept of equality of opportunity for children with disabilities. We dedicate MAIN to the purpose of securing freedom for children with disabilities and empowering these children to master their own destinies. For the purposes of establishing the framework and foundation of MAIN, and seeing our first project through to its completion, TASH is sponsoring MAIN as a "project of TASH." TASH and MAIN welcome the partnership of additional individuals and groups as co-sponsors. Co-sponsorship is critical to the provision of necessary person-power, supplies, equipment and funds needed in our work.

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Seeking Individuals with Disabilities To Be Peer Reviewers

OSERS has contracted with Educational Services, Inc. (ESI) to provide assistance in the review and management of discretionary grant applications. ESI seeks qualified individuals with disabilities from diverse backgrounds and minority reviewers who can provide unique perspectives. Proposal areas could include special education, independent living, assistive technology, housing, employment and professional training.

Review of these applications will require individuals who are knowledgeable about the subject area, sensitive to the needs of the field and competent in determining the qualities needed for a successful project. Each review panel will consist of 3-5 reviewers and a panel manager from OSERS.

Reviewers are required to travel to Washington, D.C. for 2-3 days. Travel and accommodation expenses will be covered. Reviewers will receive an honorarium of $100 per day.

Reviewers may receive the applications prior to coming to Washington, or they may receive the applications on site and review during their stay.

If you are interested in learning more about becoming a peer reviewer of OSERS, or would like to complete an application, e-mail your name, address and telephone number to Marcie Goldstein at MARCIEGAME@aol.com

TASH gratefully acknowledges the support of the following corporate participants in the 1998 Annual Conference:

Gray Line of Seattle
Greater Seattle Chamber of Commerce
Microsoft Corporation
Seattle-King County Convention & Visitors Bureau

Our sincere thanks are also extended to the following businesses for their generous donations of door prizes:

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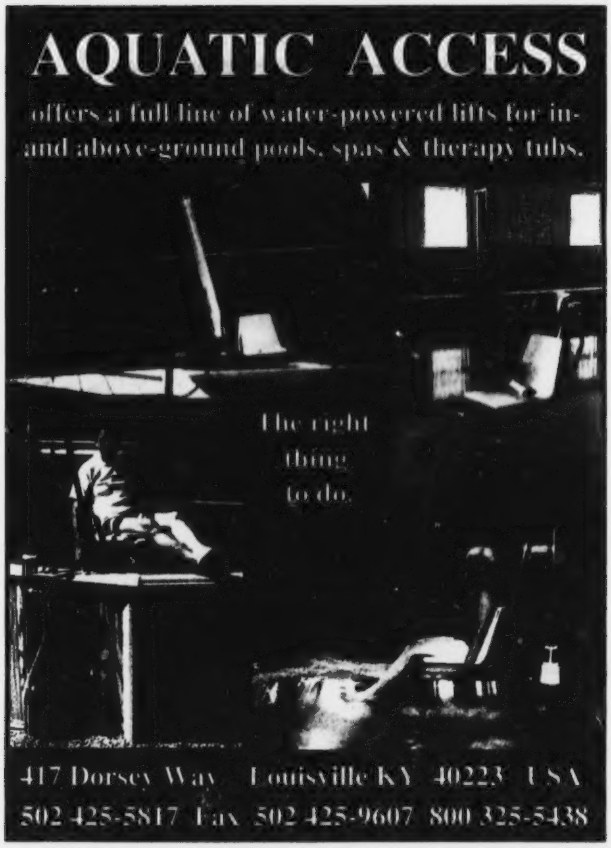
See's Candies
Unexpected Productions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❦

It is with deep sadness that we announce
that our friend and fellow TASH-SN board member,
Ed Jolly, has passed away.
Ed's unfailing optimism and work on
behalf of people with disabilities in the
Las Vegas community buoyed us all.
He taught us all that kindness and
genuine caring do have a place in our
mission to provide opportunities for community
inclusion and employment for all.
Although we all worked together for only a
short time, Ed's spirit will continue to
live on through all of us. We offer our
heartfelt thoughts to his family of friends,
co-workers, and church community members.

❦

The Board of TASH-Southern Nevada
Mark Moody, President

Open Forum on Access to Outdoor Recreation

Friday, December 4, 1998
10:30 AM-11:30 AM

Facilitator: Cynthia Burkhour

TASH is represented by Cindy Burkhour, Convener of the Leisure and Recreation Interest and Action Group on the Outdoor Developed Areas Regulatory Negotiation Committee of the US Access Board. This group of negotiators from across the country, representing both people with disabilities and providers of outdoor recreation opportunities, has been charged by the US Access Board with the task of developing accessibility design rules for outdoor recreation areas such as picnicking, camping, trails, etc. for implementation under the Americans with Disabilities Act. This open forum will provide an opportunity for input by the TASH membership to our representatives. A brief outline of the progress to date and the future activities of the committee will be discussed. This is your opportunity to share accessibility to outdoors for ALL people.

Yoga In The Morning

Instead of coffee and donuts, or worse . . .
some of us thought it might be nice to
start the day off practicing Yoga.

The practice of Yoga is an ancient form of healing and fitness for the entire body, mind and spirit. It doesn't matter what your present physical ability or condition is, or what you can or cannot do. There is no competition — as you practice, you will do better and feel better. This is a time of day for anyone who wants to explore peace of mind, and energize yourself for the day through Yoga. We'll also do breathing exercises and meditation.

See you at 7:00 AM each morning.
If you want, bring a towel.
Instructor: Alan Berger

VOCATIONAL SERVICES DIRECTOR

✦ ✦ ✦

Wayne Community Living Services, Inc. (WCLS) is a private, non-profit agency that supports over 1,700 people with developmental disabilities and their families in Wayne County, Michigan. WCLS is an internationally recognized leader in the deinstitutionalization movement. Along with housing, WCLS supports people with job placement and clinical services. WCLS is highly oriented toward full inclusion into the community, with special emphasis in supporting people in real job situations.

We are currently seeking a creative, multi-talented person to administer our supported employment program. Essential skills include grant writing, and the ability to work with private industry and management information systems. Qualified candidates should be able to provide strong values towards overcoming barriers to employment for people with significant disabilities. Bachelor's Degree in Human Services area and three years experience working with people with developmental disabilities preferred.

Exceptional fringe benefit package, including vision, dental, health, life, short/long term disability, deferred compensation plans, 5 weeks paid leave time the first year, and a highly competitive salary range ($34,034 to $51,156).

✦ ✦ ✦

SEND RESUME OR CONTACT:

Wayne Community Living Services, Inc.
Human Resources
(734) 722-4089
Fax: (734) 467-7646
35425 Michigan Avenue West
Wayne, MI 48184-1687

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TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Executive Board

Liz Healey, *President*
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MEMBERSHIP INFORMATION

Referred by:

Name:____________________

Address:____________________

City/State/Zip:____________________

Telephone: (   ) __________ Fax: (   ) __________

E-mail: ____________________

Is the above your
work address   home address
other________________

Please Check Appropriate Categories
(not more than three):

( ) Administrator/Adult Services
( ) Administrator/Education
( ) Administrator/Other
( ) Adult Service Provider/Staff
( ) Behavior Specialist
( ) Case Manager
( ) Early Childhood Services
( ) Educator/Teacher
( ) Gov. Personnel (Federal, State, Local)
( ) Interested Individual/Advocate/Friend
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional Public Policy Advocate
( ) Professor/Instructor (College/University)
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
( ) Student (College/University)
( ) Supported Employment/Day Personnel
( ) Other

Moving?

Please notify TASH of your new address.

General Membership (individual)	$88
Agency/business/university/college/library/school (allows 3 conference attendees at the member rate)	$200
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship)	$45
Family (group rate)	$136
Lifetime Member	$1000

Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada. Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information:

( ) Mastercard ( ) Visa ( ) Discover

Card Number____________________

Expiration Date____________________

Signature____________________

( ) I would like to arrange to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

If you are applying for a student membership, please provide the following information:

Department____________________

College/University____________________

Student I.D. Number____________________

Anticipated year of completion____________________

( ) Add $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone:410/828-8274 Fax: 410/828-6706

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Phone: 410/828-8274, FAX: 410/828-6706, TDD: 410/828-1306

Address Correction Requested

AUGUST 1998

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Newsletter

CRIMINAL JUSTICE AND Human Rights Issues

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 108 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

From the Executive Director

BY NANCY WEISS

It was just a list - names, dates, places, a few words about circumstances, but I read it with tears streaming down my face. The spreadsheet I received from the newspaper reporter in Connecticut couldn't have begun to convey the human suffering that had been caused to the victims and their families.

Tristan, a sixteen year old boy had died of asphyxiation in March of this year while being held facedown on the floor with a towel stuffed in his mouth. Sandra, a forty-five year old woman had died in a Utah facility in January, 1998, after being left in restraints, unchecked, for ten hours. Edith, age fifteen, had died in February of this year while being restrained for not giving a family photo to staff. Earl, a nine year old little boy had died in 1995 while being restrained facedown for forty-five minutes by staff at his community residence in Michigan. Jason, age twelve, had suffocated while being restrained facedown with staff sitting on top of him at a place ironically called "KidsPeace." In all, there were 143 names on the list.

There is an important story behind this tragic list. In April of 1997, Robert Rollins, a twelve year old boy, died while being restrained at the Devereaux School in Connecticut. Less than a year later, in March, 1998, another Connecticut child, 11 year old Andrew McClain, was killed under similar circumstances. Andrew died while being restrained face down at a Connecticut facility called Elmcrest. When the second child died in the space of a year, Dave Altimari, a reporter for the *Hartford Courant*, began to wonder if two kids dying this way within a year was a fluke. He set out to find out how many people die while being restrained in

Continued on page 3

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail dmarsh@tash.org
- **For questions about the 1998 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail knelson@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail mroth@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions or advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail pnewton@tash.org
- **For information on the Journal (JASH), call:** Lori Goetz, Editor-in-Chief, at (415) 338-6230, e-mail: lgoetz@sfsu.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

Continued from page 2

facilities for people with disabilities nationwide.

Altimari assembled a team of reporters. Together they spent several months collecting information about people who have died while being restrained in state institutions and community facilities across the country. TASH played an active role in this effort by putting out a call to members and friends over the Internet. TASH received sixty-five responses. Some people sent newspaper articles, others remembered situations but did not know dates or names, others just wanted to be informed of the results of the study. Where details were not provided, Altimari and his team went to work filling them in. Every case was verified.

The results of Altimari's study were horrifying. He and his team were able to verify 143 instances since 1986 in which people with disabilities had died while being restrained. The investigative team from the *Hartford Courant* sent their data to the Center for Risk Analysis of the Harvard School of Public Health for analysis. The Center concluded that deaths of this nature are severely under reported. They found that New York State had done the best job of record keeping.

Based on the New York data, the Harvard Center for Risk Analysis estimates that between 50 and 150 people die each year at the hands of staff while those staff are restraining them, supposedly for their own safety or the safety of those around them. That's 1 to 3 senseless deaths a week. Altimari and his staff looked only at deaths that occurred in facilities for people with developmental disabilities and similar facilities for people with psychiatric diagnoses. This means that **these figures do not include people who have died while being restrained in nursing homes, boarding homes, prisons, or at the hands of police.**

Each story is a tragedy. At the Fairview Developmental Center, in Huntington Beach, California, a schoolteacher killed a fourteen year old young man who had autism and mental retardation by rolling him inside an exercise mat in an effort to control his behavior. She was arrested. Testimony showed that she had put a diaper across his face to block his vision, rolled him in the mat, sat on the folded end of the mat and kept the student there for more than ten minutes until he stopped kicking. A few minutes after she unrolled the mat the teacher realized that the student had not gotten up and appeared limp. He died after being transported to a local hospital. The teacher's attorney argued that lay people might consider her reaction to the student's behavior improper but that a classroom full of autistic students is "a different world." "These are socially undesirable people," the attorney went on to argue, "sometimes what a teacher has to do may seem strange and distasteful to others." The judge dropped charges against the teacher and dismissed the case, saying that he had no doubt that the teacher had caused the boy's death but that her actions were "between her and her conscience and not something for a court of law."

The results of Altimari's study were horrifying. He and his team were able to verify 143 instances since 1986 in which people with disabilities had died while being restrained. The investigative team from the *Hartford Courant* sent their data to the Center for Risk Analysis of the Harvard School of Public Health for analysis. The Center concluded that deaths of this nature are severely under reported.

What makes this story unusual is not that the teacher's actions went unpunished, but that she was arrested at all. In the vast majority of instances, the staff involved were not arrested; in many of the cases there was not even a formal, internal investigation. Most staff are cleared of any wrong doing and return to their jobs working with people with disabilities. In only a fraction of the cases were the staff people involved prosecuted.

The lawyer's statement that "these are socially undesirable people" was a common theme as well. One coroner, when pressed for a cause of death, said that he couldn't release that information as the case was still under investigation. "I can tell you this, though" he said, "this was a problem kid." People with disabilities are devalued in life and their deaths are judged by some as being of less significance than the deaths of other.

Most staff are cleared of any wrong doing and return to their jobs working with people with disabilities. In only a fraction of the cases were the staff people involved prosecuted.

On Sunday morning, January 10, 1989, David, a thirty-nine year old man who had severe mental retardation, returned to his living area at Winfield State Hospital and Training Center. David asked that the TV be turned on. One of the aides told David that residents were not allowed to watch TV during the day and gave David a magazine. David became upset. He threw the magazine and grabbed the aide's shirt. The aide moved away. David slid from his chair to the floor. A male aide told David "We don't lay on the floor here." David grabbed this aide's hair. The two aides placed David in a "personal control" position. A third aide came to assist. The male aide straddled David while one of the other aides left to get the "rollerboard". The male aide who was straddling David lifted his weight off of him. David no longer struggled. The aides noticed David's lips were turning

Continued on page 27

The Role of Self-Advocates in the Justice System

BY LIZ OBERMAYER, TASH BOARD MEMBER

First I would like to tell everyone why I got involved in the self-advocacy movement. I always enjoyed politics. When I was growing up, my family was always talking about politics. I tried my best to keep up with the discussion, but somehow I just couldn't. This frustrated me because I still really enjoy learning and talking about politics.

When I heard about self-advocacy, I thought it was like politics. I say this because I think if people really want to make a difference then we need to talk to people who can help make that happen. I think that for issues such as closing institutions or changing laws to become a reality, we as self-advocates need to deal with people like governors and congressional representatives, and sometimes even the president. And it is important for us, as self-advocates to sometimes focus our efforts on more than a single issue. Although the closing of institutions is of great importance, the role of self-advocates in the justice system requires attention, too.

When I lived and worked in New Jersey, the politics of self-advocacy wasn't apparent to me. I saw people making friends and having parties. I agree that a part of self-advocacy should include having fun and interacting socially because that's part of life. It also has to include helping people make their own lives better and that's the part of self-advocacy that wasn't apparent to me at the beginning.

It soon became clear to me that people in New Jersey weren't interested in self-advocacy the way I was, so I began to look someplace else where I could make a difference. I continued working in a library in New Jersey because I enjoyed the work, but at the same time I started to become involved on the national level with Self Advocates Becoming Empowered (SABE). In 1991, at the Second National Self-Advocacy Conference I was elected to represent my region, which extends from West Virginia to Pennsylvania. I soon found myself with a lot of responsibilities — including being the Vice President — which I gladly accepted.

In January of 1996, I asked my friends who were involved with SABE if they knew where I could obtain a full time paid position working on self-advocacy issues. No one had the money to hire me at the time. So I continued my volunteer self-advocacy efforts while looking for a full time position. It was about that same time that I attended a national committee meeting and a friend of mine asked me if I had ever heard of a man named Johnny Lee Wilson. I told him I hadn't. My friend told me the story of Johnny Lee Wilson, a man with a disability who had been falsely accused of a crime and jailed. I remember getting upset and scared. I thought that if it could happen to Johnny Lee Wilson, why couldn't it happen to me? Johnny Lee has a disability like I do, so my disability could be the reason why the police would "pick me up." I may not have the exact same disabilities as Johnny Lee, but the police could look at how I walk or talk and they might assume I am under the influence of drugs or alcohol.

■ ■ ■

And it is important for us, as self-advocates to sometimes focus our efforts on more than a single issue. Although the closing of institutions is of great importance, the role of self-advocates in the justice system requires attention, too.

■ ■ ■

I became interested in helping people such as Johnny Lee Wilson get out of jail, so I volunteered on my days off to work on a criminal justice project. I believed in the cause and was proud of my contribution to this effort. In my opinion, Johnny Lee Wilson was in jail for no reason other than the fact that he had a disability. Johnny Lee was falsely accused of murdering an elderly woman. He signed the confession because he didn't understand what he was signing. This is true for a lot of people with disabilities. Johnny Lee received a pardon from the Governor of Missouri and he got out of the jail a couple of years ago. However, there are still many people with disabilities falsely accused and imprisoned in the criminal justice system.

Another reason why people with disabilities should be involved in the criminal justice issue is because we, as people with disabilities, know what kind of language is easy for us to understand. We are, in a way, the experts on how the police and law enforcement officials should talk to us. I will share a story with you about language.

I attended a conference on the treatment of people with disabilities in the criminal justice system. While there, I was sitting down with some friends of mine, including people at the UAP at Temple (Pennsylvania), and we were talking about miranda rights. I asked, "what are they?" They told me that reading miranda rights to a person involves telling them that they have the right to have a lawyer. I said, "yes, I know what they are... they are my rights." But I had never heard the term "miranda rights" before. Was that my fault? I say no, and it wouldn't be the police officer's fault either, because the term "miranda rights" is the accepted terminology used by police officers and others in the law enforcement field. We need to make sure that people with disabilities are familiar with phrases like that.

Although I was learning a great deal about criminal justice issues, my advocacy on behalf of people with disabilities still wasn't a full time job. I had my heart set on a full time job doing self-advocacy work and I knew that I could find one because some of my friends had jobs doing this kind of work.

Shortly thereafter, I was hired as the Chair of an Administration on Developmental Disabilities (ADD)-funded project called the National Advisory Group for Justice, which is managed through PILCOP (Public Interest Law Center of Philadelphia). The idea of writing this grant for ADD came from self-advocates. The purpose of the grant is to educate people on the issue of the treatment of people with disabilities in the criminal justice system. Most of the people who work on this project are people with disabilities. However, it makes me sad and angry to think that many self-advocates in this country are not involved in this issue.

This has to be one of our concerns because people with disabilities are the ones who are put into jails for no reason other than the fact that we have a disability. It is true that some of us are jailed for crimes that we might have committed, but in those instances do we get due process? In most cases, people with disabilities don't get due process because many people who work in the criminal justice system do not value us.

We have to take ownership of these issues — the criminal justice system as well as the closing of institutions. They both can and do affect us as people with disabilities. Who better to advocate on behalf of these issues than people with disabilities? I can't think of anyone!

Creating Futures Together

TASH Conference '98

SEATTLE, WASHINGTON

1998 TASH
Conference Registration Form
Creating Futures Together

Seattle, December 2-5, 1998

Mail form to: TASH
29 W. Susquehanna Avenue, Suite 210, Baltimore MD 21204-5201
Fax form to: 410-828-6706
Questions? Call 1-800-482-TASH

The registration form can also be found at our Web site at www.tash.org
You may use this form to register for the conference, become a TASH Member, or both!

Please Print

First Name ____ Last Name ____
Preferred Badge Name ____
Agency/School/University ____
Mailing Address ____
City/State/Province ____ Zip/Postal Code ____ Country ____
This address is: home work school other ____
Billing address (if different from above) ____
Agency/School/University ____
Mailing Address ____
City/State/Province ____ Zip/Postal Code ____ Country ____
Daytime Telephone ____ Work Telephone ____ Fax ____ e-mail ____
This address is: home work school other ____

Please circle the appropriate numbers that describe your affiliation (not more than 3):

1. Administrator/Adult Services
2. Administrator/Education
3. Administrator/Other
4. Adult Service Provider/Staff
5. Early Childhood Services
6. Government Personnel
7. Legal Services Provider
8. OT/PT
9. Parent/Family Member
10. Professional/Public Policy Advocate
11. Professor/Instructor (College/University)
12. Psychologist
13. Regular Education Teacher/Admin.
14. Related Services Provider
15. Self-Advocate
16. Social Worker
17. Speech/Language Pathologist
18. Special Ed. Teacher/Support Spec.
19. Staff Development/Trainer
20. Student
21. Supported Employment/Day Personnel
22. Other ____

Please fill out this section only if you are registering for the conference:

TASH Membership: I am a current member Individual Agency
Membership# ____
If you are a student member, please list your Student ID# ____
I am becoming a member now *(please be sure to enter the applicable cost on the reverse side)*
I am renewing my membership now *(please be sure to enter the applicable cost on the reverse side)*

Optional Conference Information Requested (please request by October 16, 1998)

Accessibility Details
Sign Language Interpreter
Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited and there is a nominal fee.)
Roommate Referral Program
List any accommodation needs ____

Application for CEU credits have been made to the following organizations:

National Association of Social Workers, American Physical Therapy Association, The American Occupational Therapy Foundation, American Therapeutic Recreation Association and local education agencies.

I would like to request further information on CEU credits List Type ____

To Become a TASH Member or Renew your Membership NOW. . .

You may also use this form to become a member at the same time you register for the TASH conference! This allows you to register for the conference at the reduced TASH member rate (see other side for member registration rates) or, use this form to join as a member without registering for the conference.

Membership rates are listed below. Determine the appropriate membership category, be sure to fill in the applicable rate on the reverse side of this form when entering payment information, and include payment at the time you submit your conference registration payment.

General International Membership (individuals)	$88.00
Agency/Business/University International Membership	$ 200.00
Self-Advocate, Parent, Full-Time Student	$45.00
Family International Membership (2 People)	$136.00
Lifetime International Membership	$1,000.00

(Add $10.00 to memberships in Canada and $25.00 to memberships outside of the U.S. and Canada to cover additional postage costs.)

Fill in appropriate membership rate on Line 8 on reverse side of this form.

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CONFERENCE REGISTRATION FORM

1998 TASH Conference - Creating Futures Together
December 2-5

Registration Rates 1998 Conference	Current or Joining International Member	Non-Member	Please Enter Applicable Cost
General	$199	$305	
Student/Paraprofessional/Parent (Professional)	$135	$229	
Self Advocate/Parent (non-professional)	$ 49	$ 79	
One Day Only Thurs Fri Sat	$ 99	$129	

1. Cost of Conference Registration from above .... 1. ________

2. Subtract Discount if applicable. **(Note: Only one discount can be applied.)**

   a. Subtract $20 per registration for groups of 5 or more registering for the full conference (all registrations must be mailed in the same envelope) .... 2a. ________

   b. Subtract $50 per full conference registration for a regular education teacher registering with a special education teacher, a paraprofessional, or related services personnel; or for any support staff person registering with a self-advocate (must be mailed in the same envelope). Indicate name of person with whom you are registering:
   ________________ .... 2b. ________

3. Add $40 late fee if you are registering after November 13th. After November 13th, all registrations will be on-site .... 3. ________

TOTAL Conference Registration Fee .... 4. ________

TASH Techs:

TASH Members	$65	1st Choice TASH Tech # ________
Non-Members	$80	2nd Choice TASH Tech # ________
Self-Advocate/Parent	$40	

Note: There is no charge for the Chapter Leadership TASH Tech.

5. Add Cost of TASH Tech (full day pre-conference workshops, see descriptions, page 7) .... 5. ________

6. Add $85 to attend the Special Pre-Conference Symposium on Dual Diagnosis .... 6. ________

7. TOURS
   a. Add $42.00 for the Grapes & Hops Tour (contact TASH office for a description of tours) .... 7a. ________
   b. Add $28 for the Seattle City Tour (contact TASH office for a description of tours) .... 7b. ________

8. Add TASH Membership Dues if you are joining TASH International or renewing with this application (see rates on front page of this form) .... 8. ________

9. Add $15 to also join your TASH Chapter (only applicable if you are joining or renewing membership for TASH International now) .... 9. ________

10. Yes, I will add $5 to support a self-advocate to attend the conference .... 10. ________

TOTAL Enclosed (Lines 4-10) .... ________

Payment Terms **TASH Federal ID#:51-0160220**

Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from cancellations received before November 6, 1998, and added to purchase orders not paid within 30 days after the conference. No refunds will be given for cancellations after November 6, 1998. A $15.00 fee for returned checks or unauthorized charges will be assessed.

Check enclosed Purchase Order/State Voucher No. ________________

Visa Mastercard Discover Card Number ________________ Exp. Date ________

Signature ________________________________

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Creating Futures Together

TASH Conference '98

SEATTLE, WASHINGTON

Tentative Conference Agenda

Tuesday, December 1, 1998

8:00 PM - 10:00 PM	Registration Open

Pre-Conference Activities
Wednesday, December 2, 1998

7:30 AM - 8:45 AM	TASH Tech Registration
8:30 AM - 4:30 PM	Club TASH Day Care/Youth Activities
9:00 AM - 4:00 PM	TASH Tech Workshops
9:00 AM - 4:00 PM	TASH Chapter Development and Leadership Training
2:00 PM -8:00 PM	TASH Conference Registration
5:00 PM -7:00 PM	Opening Reception in the TASH Exhibit Hall

Thursday, December 3, 1998

7:30 AM - 1:00 PM	Registration
7:30 AM - 3:00 PM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 3:15 PM	Conference Sessions and Poster Presentations
3:30 PM - 5:30 PM	Plenary Session
5:30 PM -7:00 PM	No-Host Reception

Friday, December 4, 1998

7:30 AM - 11:00 AM	Registration
7:30 AM - 3:00 PM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 3:15 PM	Conference Sessions and Poster Presentations
3:30 PM - 5:30 PM	Plenary Session
5:30 PM - 7:00 PM	TASH Reception (sponsored by WA-TASH Chapter)

Saturday, December 5, 1998

7:30 AM - 9:00 AM	Registration
7:30 AM - 12:00 PM	TASH Exhibit Hall Open
8:30 AM - 1:00 PM	Club TASH Day Care/Youth Activities
8:00 AM - 12:45 PM	Conference Sessions and Poster Presentations

— LOCATION —

Seattle Sheraton Hotel and Towers
(Headquarter Hotel)
1400 Sixth Avenue
Seattle, Washington 98101
Phone: 206-621-9000

Rates:
$123.00 Single • $133.00 Double • $20.00 Additional Person
Room tax is an additional 15.6% per night

Washington State Convention and Trade Center
(Location of Exhibits and Conference Sessions)
800 Convention Place (1 block from Sheraton)
Seattle, WA 98101 • 206-727-2814

ALTERNATE HOTELS

Seattle Hilton
Sixth and University • Seattle, Washington 98111
206-624-0500
Rate $112.00 single/double, plus 15.6% tax
$15.00 extra person
2 1/2 blocks from the Convention Center

Seattle Crown Plaza
1113 6th Avenue • Seattle, WA 98101-3048
206-464-1980
Rate: $115.00 single/double , plus 15.6% tax
2 1/2- 3 blocks from Convention Center

— AIRPORT —

Seattle-Tacoma International Airport
16 miles south of Downtown
Average cost for taxi $30, shuttle $18.00, bus $7.50

— AIR TRANSPORTATION —

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Community Inclusion & Personal Safety

BY RICHARD SOBSEY

Dick Sobsey is Director of the JP Das Development Disabilities Centre, University of Alberta, Edmonton, Alberta, Canada.

Our son, David, was born in 1990 with a "severe" developmental disability. I had already been working with people with developmental disabilities as a professional since 1968, and I had devoted my work to violence and abuse prevention since 1986. I had learned a lot as a professional and as a researcher, but I still had a lot to learn as a parent. Here are some things that I think that all parents of children with disabilities should know about keeping their children safe.

Kids with disabilities are at greater risk for abuse than other children. Although studies differ on whether their risk is 2, 3 or even 4 times as high as the risk experienced by other kids, there is remarkable consistency in the finding of elevated risk. This elevated risk, however, is not the same for children of all ages. It is relatively small for very young children but increases as they get older and approach adulthood. **Research also provides good reason to believe that the risk of abuse is much higher in special programs, residential facilities, and institutions than in natural families, neighborhood schools, and community living alternatives.** It is important to note that research comparing the risks of abuse in inclusive living environments with segregated alternatives is rare and plagued by procedural difficulties. Nevertheless, all of the research that is available favors community living.

David is eight now. He attends a regular classroom in our neighborhood school. We chose inclusive education because of its educational and social advantages, but we believe it also keeps him safer. Here is an example of why. Several years ago, I wrote a chapter on teaching people with developmental disabilities personal safety. One of the things I suggested is creating opportunities for them to meet local police officers.

So, when David was 6, I decided to practice what I preach and show him where the local police station was. Our city has adopted a community policing philosophy and there is a small station a few blocks from our house. We went in and I stumbled for words to explain why we were there as the officer in charge approached us. She smiled and greeted David by name. Even though the officer in charge was a stranger to me, she was the mother of a child in David's school, and she knew him pretty well. It was coincidence, of course, but it is a coincidence that was possible because community policing tries to ensure that officers live and work in the same communities. Walking home from the police station, six more people greeted David by name.

In the past three decades, **there have been hundreds of studies of risk for child abuse, and the most consistent risk factor identified has been isolation of families from their communities.** David could have attended a district site for students with disabilities that is 114 blocks from home. He could have spent 90 minutes commuting each day instead of getting to know people in his own community.

One other factor consistently has been identified as having protective powers. Attachment and natural and healthy human bonding helps inhibit violence. Most human beings experience feelings of aggression toward others from time to time. However, the vast majority of us learn to control those feelings and are reluctant to hurt others.

Disinhibition is a term used to describe how some people overcome that inhibition to act out their violent impulses. Dehumanization and depersonalization are terms used to by researchers studying violence to describe how thinking of another person as less human, less like one of "us," allows aggression to come out. The primary tools for depersonalization are labeling and distancing. **Segregated schools increase physical and social distance, constructing the world as "us and them." In doing so, it permits violence toward "them."** No one in this world is completely safe from violence, but building healthy families and inclusive communities minimizes the risk.

Dick Sobsey is the author of Violence and Abuse in the Lives of People with Disabilities. For further information, Dr Sobsey may be contacted at (403) 492-3755 (phone); (403) 492-1318 (fax) or via e-mail <dick.sobsey@ualberta.ca>

TWIN WINS SPECIAL EDUCATION CLOSE TO HOME

BY ESMERALDA BARNES, JOURNAL STAFF WRITER

Reprinted courtesy of The Journal, Fairfax, Virginia

Jill Jacobs refused to give up the fight to convince Fairfax County to place her son with a disability in a neighborhood school with his twin sister.

Last Friday [August 7, 1998], Jacobs got her victory. The school system reversed an earlier decision, ruling that Jacobs' 5-year old son, Collin, may enroll in kindergarten at nearby Fort Belvoir Elementary instead of Bush Hill Elementary, in the Alexandria portion of Fairfax County 14 miles from the Jacobs' Fort Belvoir home.

School system officials had insisted that a special program at Bush Hill would be better equipped to serve Collin's needs. Collin and his twin sister, Laura, have cerebral palsy, a central nervous system disorder that can cause speech problems and mild to severe paralysis.

The family lost a battle last year to place Collin in preschool at his neighborhood elementary school. But after more than a year of phone calls, letter-writing and meetings with advocacy groups and school officials, the Jacobs family is celebrating Friday's victory with music, dance and McDonald's.

Collin now will join Laura, who has a milder form of cerebral palsy, and his oldest sister Sarah, 10, who will be a sixth-grader at the school. The newly built school will open this September and is two miles from the Jacobs' home.

"We are so happy," said Jacobs. "This is a real victory for everyone - our family, our community and for families nationwide. He'll ride the same bus with his chums and his sisters," she said.

Instead of traveling 45 minutes to get to school, the ride is no more than five minutes, she said. Advocates for [people with disabilities] say the Jacobs' case - much like the plight of other disabled families in the county - illustrates the power of persistence in fighting for [the rights of students with disabilities] to do everything from marching in graduation ceremonies to attending their neighborhood schools.

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Jacobs praised school administration for being "very progressive and moving the school system in a new direction, where new ideas on how to educate special education children are taken seriously."

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For example, school officials in Spring 1997 allowed a Chantilly High School senior with disabilities to march with her general education classmates, after initially refusing because they said the girl had not completed the necessary year of job training to complete her degree requirements. But her parents pressured officials by going to the media and then school board members, who ultimately allowed her to march with her Chantilly High classmates and then take the year of job training.

Through persistent calls and letters, Jacobs attracted the attention of national disability advocates and the pro bono help of a law firm and a public relations company. "I just kept calling people and saying 'Please help me, please help me,' until someone did," she said. "And I talked to adults with the same disability as Collin to make sure I was doing the right thing. I had faith in my child and in myself that I knew what was best for him."

School officials would not discuss Collin's case or the support he will be offered at the school. However, Jacobs said Collin will be in a general education kindergarten class and receive extra assistance from physical and speech therapists and others trained in special education.

Jacobs praised school administration for being "very progressive and moving the school system in a new direction, where new ideas on how to educate special education children are taken seriously."

"I saw a major change in the whole atmosphere here," she said. "We are on the wave of this major shift in attitudes countywide."

But Alice Farling, who oversees special education in the county, said the school system's action Friday was more "evolutionary than revolutionary." "We evaluate each child's situation individually, but we are trying to be more creative

Continued on page 10

TWIN WINS SPECIAL EDUCATION CLOSE TO HOME

Continued from page 9

and offer better services to all of our special education students," she said.

There are roughly 20,000 special education students in the county, and 80 percent of those are in their neighborhood schools. "But the law does not require us to offer every program and service in a student's neighborhood school," she said. "But when we can, and depending on the child's needs, we are trying to offer students better services as close as possible to their neighborhood schools, because we know the value of children."

UPDATE:

The new school year began in Fairfax County, Virginia a few days ago, just as it did in thousands of school districts around the country. We caught up with Jill and asked her tell us about Collin and his sisters' first impressions of the new school year.

"For me, Collin's first days of school have been wonderful. A few little glitches here and there, but absolutely nothing that we did not remedy by putting our heads together. I cannot explain the feelings I had on the first day and the couple of days leading up to it. Cliche, I know, but it was truly bittersweet. I can tell you that I am grateful and joyous to be able to experience such typical mom-of-kindergartners emotions.

As for Collin and his sisters, well. . .they are loving school, loving riding the school bus together, loving life! Sarah was made a "bus monitor," an honor that 'fulfills a life-long dream' (her words!) for her, so she is psyched!!! Laura is a bit disappointed. She laments that the other kindergarten students just 'mill around' and are not at all concerned with books and pencils and paper. She says she came to school for an education, and she has no idea what her teacher is thinking by not teaching real stuff.

Each morning as he heads for the bus, Collin's face looks as though it might actually burst from his humongous grin. He adores his teachers and the bus driver, who happens to look exactly like Santa Claus! His teachers, Miss Bourque and Mrs. Firer, are quite wonderful at getting Collin in with the other kids. On the first day, while on the playground, Mrs. Firer whipped Collin out of his wheelchair and chucked him down the slide! BRAVO, teacher, BRAVO!

Please extend our family's sincerest thanks to all of the TASHers, advocates, families, friends, educators, and anyone else you know who lent a hand with this effort. There is no way to repay the favor but with our undying love and commitment to freedom for all children."

As ever — In freedom,
Jill Jacobs

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Making Your Handout Materials Accessible

BY DENISE MARSHALL, DIRECTOR OF TRAINING AND TECHNICAL ASSISTANCE

Under Title III of the Americans with Disabilities Act (ADA), places of public accommodation are required to ensure that people whose disabilities affect hearing, vision, speech, or cognition are provided with effective communication through auxiliary aids and services that enable them to fully benefit from facilities, services, goods, and programs. Among many other venues, a conference that is open to the public falls under this category.

In other words, communication must be equally effective for everyone! As such, **we have asked presenters at the TASH Annual Conference to take the responsibility to provide any handout materials in alternative format.** Participants at the conference do not register for specific workshops in advance, and may register for the conference on-site, therefore it is not possible to specify what types of alternate format will be requested. Because computer disk is perhaps the easiest and most versatile method, at a minimum all presenters are expected to have material available in this format. The following information may help you in preparing handouts that are accessible.

Computer Diskettes

Disks can be used for many purposes, such as for use with computers with voice output that can "read" data aloud; to print out Braille text or large print. Save your file in an ASCII format to maximize utility. It is recommended that 2-3 copies of material be available on disk.

Large Print Materials

Some people with visual disabilities can read large print. Large print materials can be made at low cost using a photocopier or a personal computer. Use a 16-point type size or larger (18 is best). The type should be double-spaced and printed on a high-contrast background.

All Printed Materials

Prepare text according to the following principles to maximize legibility (this benefits everyone, in your presentation):

- Make information clear and easy to understand.
- Be conscious of the glare and background of the paper that you are using. Black lettering on yellow, off-white, or gray paper provides maximum legibility, with less glare than plain white paper.
- Leave right margins ragged; this leaves words evenly spaced, making text easier to read .
- Use lower case letters with initial capitals; this is more legible than all capitals.
- Minimize the number of typefaces used on a page.
- Use simple layout design

Audio Tapes

Some people who are blind or visually impaired cannot or prefer not to read Braille or large print, and find tapes more useful. You can make the recordings yourself or you may wish to have your material recorded professionally.

Recording tips for doing it yourself:

- Label the tape in type and in Braille. On each side of the tape and on the cassette label;, identify the side number, the document title, and the page range being read.
- Record in an area where there is no background noise.
- Read at a moderate pace and articulate words clearly.
- At the end of the recording, identify who has done the reading.

Captioning for Video Tapes

Captioning is the process by which the audio part of a videotape or film is transcribed and made visible on the screen to be read by people with hearing disabilities. Closed captions are visible only if the television is equipped with a decoder; open captions are always visible. All Tapes to be shown at the conference should be captioned. If you are renting video equipment through TASH, please notify the TASH Central Office if closed captioning will be used.

If you have questions on any of the above requirements, please call Denise Marshall at 410-828-8274, ext. 103 or send an e-mail to dmarsh@tash.org

FOR MORE INFORMATION...

The following organizations address aspects of communication accessibility.

ADA Communication Accommodations Project (ADA-CAP)
American Foundation for the Blind
Governmental Relations Department
1615 M Street, NW, Suite 250
Washington, DC 20036
Hotline on vision issues:
(202) 223-0101 voice/TDD
Hotline on hearing issues:
(202) 651-5343 voice/TDD

National Braille Press
88 St. Stephen Street
Boston, MA 02215
(617) 266-6160 voice

National Federation of the Blind
Information Access Project
1800 Johnson Street
Baltimore, MD 21230
(410) 659-9314 voice

American Foundation for the Blind
11 Penn Plaza , Suite 300
New York, NY 10001
TDD: 212-502-7662, FAX-212-502-7777
http://www.afb.org

Architectural and Transportation Barriers Compliance Board
1331 F Street, NW, Suite 1000
Washington, DC 20004-1111
(800) USA-ABLE voice, (202) 653-7834 voice
(202) 272-5449 TDD

U.S. Department of Justice
http://www.usdoj.gov/crt/ada
ADA Information Line
1-800-514-0301 VOICE
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Whenever possible you should indicate on materials that they are available in alternate formats. The following web site contains universal symbols for accessibility:

Disability Access Symbols
Graphic Artists Guild Foundation
90 John Street, Suite 403, 8th Floor
New York, NY 10038-3202
800-878-2753
http://www.gag.org/das/

My Experiences With The Criminal Justice System

BY PERRY WHITTICO, WITH BONNIE SHOULTZ

I am a 47 year old, unmarried, brown-skinned American man who is involved in a number of community organizations, including self-advocacy. I've been president of Self-Advocates of Central New York for a number of years. My disabilities include dyslexia and diabetes, and I've been involved in the mental health system because of neurologically-based speech and language disabilities. I've also been involved in the developmental disabilities system, spending several years in institutions.

I have also spent some time in jail and have had quite a few altercations with the criminal justice system. Most times the charges were suspended or dropped. Thirty years ago, I spent six months in jail for a crime I didn't do. I didn't understand the charges or how to fight them. I was very naive in the system then. They charged me with aggravated harassment; they said I had made a bomb threat over the telephone to the Syracuse City School District's Department of Special Education. It was true that I had called the department that day to set up an appointment with the psychologist to be re-admitted to school. I had been expelled for fighting but I hadn't caused the fight. Another kid had called me "nigger" in front of a bunch of white kids and I had argued with him about it. I told him, "I am not a nigger, I'm an American, and you should be more respectful to people." He grabbed me, and I punched him and I was expelled. He was seen as the victim in the situation.

When I got to the School District office to get re-admitted, there were several policemen there who said I had called in a bomb threat. They said they had a recording of me making this call. To this day, I don't know if they misunderstood my speech when I called, or whether it was someone else who made the bomb threat. They took me in for questioning, which went on for a long time, but I didn't confess to making the bomb threat. They booked me and I stayed overnight.

The next day I went to court and they gave me a lawyer. I stayed in the Public Safety Building (jail) for three months while I waited for my trial. Then my lawyer told me "We are going to trial. I think we have a deal that you can live with if you agree with it. All you have to do is get sentenced to Jamesville (the county prison) for a year, but you can get out in three months if you follow the rules and regulations." I didn't really understand much of what was going on, or that I was pleading guilty to making the bomb threat. I gave in to it because they kept saying they had a recording of my voice, and they said I could get up to five years if I didn't accept the deal. The judge gave me credit for the time I had served, and I got out of Jamesville in three months because I didn't get into trouble there. I was on parole for another month.

Since then, the police have given me warnings at different times when I got into arguments, but I've only been arrested one other time. That was two or three years ago. I had been depressed, so I took an overdose of insulin, which I take for my diabetes. I had injected 85 units; my usual dose is 21 units. After I took it, I waited a while and took my blood sugar. It was way down, so I called 911 and told them what I had done. They called an ambulance and the police.

The ambulance showed up first. I was walking out the door with the ambulance crew to be taken to the hospital. The police showed up and said they would take me to CPEP (Crisis Psychiatric Emergency Program) instead, and I got angry and walked away down the patio near my apartment building. A policeman ran after me and slipped on the pavement. His partner put in an "officer down" call and more police showed up, along with another ambulance. They were crowding me too much, even though I was asking them to give me about three feet of space so I could calm down. The situation got out of control and I ended up getting charged with resisting arrest, menacing, and use of a weapon.

In my opinion, the police didn't understand my disability and my medical conditions, and they caused even more confusion and frustration than there already was. They pepper-sprayed me three times and punched me several times. Another officer cut his hand on the gravel when he was trying to punch me — by this time I was handcuffed behind my back and down on my stomach — and he missed. The police caused most of the problem because they didn't listen to the ambulance crew or me.

Finally, I was taken to the hospital because the police called a sergeant who told them to give me an appearance ticket

Continued on page 13

My Experiences With The Criminal Justice System

Continued from page 12

rather than taking me down to the Justice Center. Then the ambulance took me to the hospital, with a police officer on board with me. He kept talking to me, telling me to calm down, but I couldn't. Because of the insulin overdose, along with the other things I had been feeling before I took the insulin and the altercation with the police, it was practically impossible for me to calm down. They took me to CPEP and kept me there for three days.

When I appeared in court, I was given a lawyer. The lawyer told me to talk to my friends about what had happened and to ask them to write letters telling about my work in the community. I got letters from the Center on Human Policy, the Developmental Services Office, Citizen Advocacy, my therapist, and my case manager. I also went to the University Hospital library and found an article describing the effects of an insulin overdose (confusion, argumentativeness, difficulty reasoning or evaluating the situation). My lawyer showed the judge the article and the letters. The district attorney kept reminding the judge that there were two officers injured in the incident, but the judge said that their injuries were their own fault. The first policeman shouldn't have been running after me, and the other one cut his hand after I was handcuffed. The judge dismissed all of the charges. Since then I have "kept my nose clean," and I have stopped taking overdoses of insulin.

I would like to give my opinions about disability and the criminal justice system. The police are trained to deal with people who don't have disabilities. They have very little training in anything that involves disabilities because they say, "We are not psychologists or doctors, we are just here to make arrests or enforce the law." When they meet someone with a disability that they think is breaking the law, they aren't equipped to adequately address the situation. They don't know what to do with someone with a mental disability. They might just try to get the person to go for an evaluation if they are upset, or they may treat the person as though they understand what is happening, even if they really don't. If the person doesn't speak in a manner the officer can understand, the officer has a tendency to stop listening because he thinks the person is speaking gibberish. It comes down to a breakdown in communication that both parties have trouble recognizing because they are too busy fighting.

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"...The police are trained to deal with people who don't have disabilities. ...When they meet someone with a disability that they think is breaking the law, they aren't equipped to adequately address the situation...they may treat the person as though they understand what is happening, even if they really don't. ...It comes down to a breakdown in communication that both parties have trouble recognizing..."

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I have one friend (I won't say where he lives) who was convicted of murder many years ago. He was convicted because he did not understand his rights and he confessed to the crime without understanding what he was doing. He did not commit this murder, but for some reason (maybe because he is black) the police and the district attorney were convinced he had done it. He was in prison for two years. A large group of people advocated for him and he got a new trial. At the new trial, he was freed because they proved he was innocent. He had to go back to an institution for a long time afterwards because the police and the community he lived in still thought he was guilty. Now he is a leader in the self-advocacy movement, and I don't think he has ever been in trouble with the police since he got out of the institution. This shows how people with disabilities can be falsely accused and convicted of illegal acts.

Even if a person with a disability commits a crime, they may not be treated fairly by the system. They can be taken advantage of in lots of ways. Their rights can be violated or taken from them without them knowing it, or they can be pushed into more frustration and confusion, like I was, because the police don't understand the person's needs. I have also seen a lot of people who have both psychiatric and developmental disabilities who have been mistreated in the system.

People with disabilities need tips on how to stay out of trouble. I have given some training on this subject at self-advocacy conferences. I used a curriculum called Right Rules that was developed by Back to Life, an organization in Texas, and published by the National Advisory Group for Justice, an Administration for Developmental Disabilities-funded project operated by the Public Interest Law Center of Philadelphia. Since I can't read, I put up an overhead and ask audience members to read each line. Then we discuss it. Here are a few of the tips:

- Try to stay calm and be polite.
- Carry an identification card.
- Tell the police "I need a lawyer" as soon as they ask you any questions besides your name and address.
- Tell the police if you have special needs.

There is quite a bit more to this curriculum and I think it works well. I hope this article will keep someone from being arrested or treated unfairly in the criminal justice system.

Reference:
Back to Life (1997). Right Rules: A Training on our Constitutional Rights. Philadelphia: Public Interest Law Center of Philadelphia, 125 S. Ninth Street, Philadelphia, PA 19107; (215) 627-2105.

Perry Whittico and Bonnie Shoultz can be reached at the Center on Human Policy at 315-443-3851.

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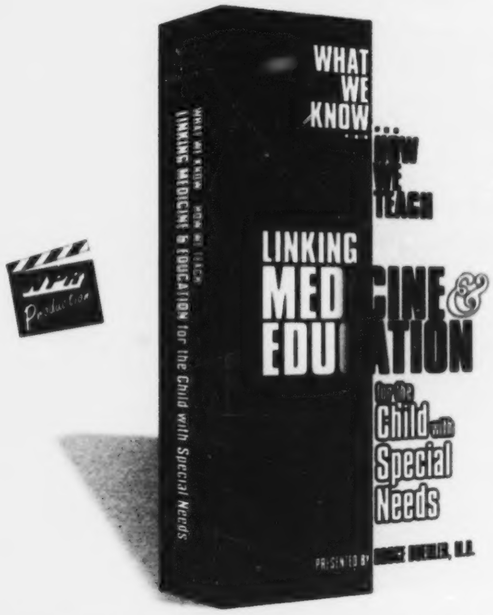
WHAT WE KNOW... HOW WE TEACH
LINKING MEDICINE & EDUCATION for the Child with Special Needs
WHAT WE KNOW...HOW WE TEACH
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Linking Medicine & Education for the Child with Special Needs

BRUCE A. BUEHLER, M.D.

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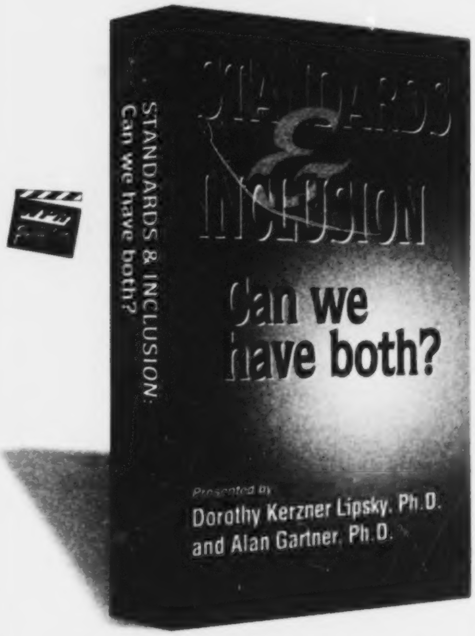

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ABOUT THE AUTHORS: ***Dorothy Kerzner Lipsky*** *is Director of the National Center on Educational Restructuring and Inclusion, and* ***Alan Gartner*** *is Dean for Research. Both are at The Graduate School and University Center, The City University of New York.*

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Communicating with People Who Have COGNITIVE DISABILITIES IN THE CRIMINAL JUSTICE SYSTEM

BY MARY F. HAYDEN

As a result of Title II of the Americans with Disabilities Act, law enforcement and court personnel are faced with making reasonable accommodations to people with cognitive and other disabilities. Communication is the first area where professionals need to think about how they are accommodating an individual with cognitive disabilities. The purpose of this article is to raise awareness of certain factors that need to be considered in communicating with persons with cognitive disabilities within the context of the justice system, and to offer a framework for further discussions and developing guidelines and procedures that ensure reasonable accommodations at all levels of our legal system.

Communicating Concretely

People with cognitive disabilities tend to think in concrete and literal terms. As a result, they may not understand the meaning of words such as parole, probation, plea bargaining, restitution, community service, and waiver of rights. It is also true that although a person may understand a word, he/she may not understand the consequences of the word. The concept of restitution may be too abstract for an individual with a cognitive disability. The person may understand and have a deep desire to pay for damages he or she caused, but may not understand all that restitution entails.

For example, people with cognitive disabilities typically live at or below the poverty level. They might not have the money to make restitution even though they want to. Unless a defense attorney is willing to sit down with a client and examine the client's personal budget to determine if restitution is possible, the attorney cannot negotiate for restitution in good faith. If it is fiscally possible for a client to make restitution, an attorney still needs to assess whether the client needs a court-appointed advocate or conservator to ensure that the client follows through with payments.

When communicating with persons with cognitive disabilities about their rights, the consequences of their behavior and choices, and their options, the safest approach is to involve an individual who is close to the person - such as a friend, family member, social worker or counselor - to help interpret what is being said and ensure that the person understands what is going on. It is important while doing this to continue talking to the person with a disability directly, rather than talking about him or her with others as though the person were not present.

Interpreting Agreement

People with cognitive disabilities frequently will agree with others even when it is not appropriate. This may occur for several reasons. They may be intimidated by authority figures. They may have been told that the police are their friends and that they should trust them; they may therefore want to please a police officer by saying what they believe the officer wants to hear, regardless of whether it is true or not. Some people with cognitive disabilities want to hide the fact that they have limitations and that they do not understand everything; they may agree with people because they know most people will not ask them to elaborate on a "yes" answer. As a consequence of a tendency to agree with others, police cannot assume that individuals with cognitive disabilities understand their rights when read to them.

Additionally, law enforcement personnel and attorneys cannot place a piece of paper in front of a person with a cognitive disability, ask the person to read the information, and then ask the person if he or she understands what it says. If the person responds in a affirmative manner, the response could mean that (a) the person did read and understand the information; (b) the person may not know how to read and said "yes" to hide an inability to read; or (c) the person may know how to read, but does not understand the information and said "yes" to avoid appearing "stupid."

To ensure that persons with cognitive disabilities understand what is said to them verbally or in writing, and that an affirmative response to any questions truly reflects a "yes" on their part, it is best to involve a person who is in a close relationship with the individual and knows the individual well. Other options are to:

- involve a legal advocate with documented professional experience with people with cognitive disabilities;
- read rights or statements or questions one at a time, asking the person to repeat what was said, and asking the person to explain the meaning of what was said before going on to the next item; or
- use an alternative format to communicate information to the person, such as pictures.

Asking Questions

Sometimes individuals with cognitive disabilities require more time to process questions than they are allowed. At times questions may be too complex or confusing, or may be worded in such a way that they lead the person to an incorrect response because of differing interpretations of the question. Complex questions should be broken down into simple, concrete questions. If the person does not immediately respond to a question, they should be allowed 30 seconds to answer, and then asked if the

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Communicating with People Who Have Cognitive Disabilities

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question should be stated again. Sometimes persons with cognitive disabilities may give responses that seem factually incorrect: this may be because they have interpreted words differently than intended. In these situations, the information can be verified with someone who knows the person well.

Open-ended questions and yes-no questions tend to be difficult for persons with cognitive disabilities. With yes-no questions, they are more likely to answer "yes" regardless of whether it's the correct answer. Either-or questions and multiple-choice questions with pictures may be more useful. It is important that investigators ask for the same information in alternative ways to determine whether answers are consistent with each other and what, if any, systematic biases are operating. Where possible, answers should be verified by independently obtained information (e.g., informants, files or observations).

Understanding Speech

Sometimes people with cognitive disabilities have articulation difficulties or limited language and, as a result, their speech may be difficult to understand. If a person is upset or nervous, his or her speech may become even less understandable. Sometimes talking with the person for awhile helps the listener become accustomed to hearing their speech pattern. It may also be helpful to do the following:

- Use simple clarification (e.g., "What? I didn't understand you").
- Re-ask the question (e.g., "Let me ask that again. I couldn't get your answer."). It may be necessary to re-ask the question a number of times. This is preferable to jumping to an interpretation which may be wrong.
- Try to calm and focus the individual (e.g., "I know you are really trying hard to answer my questions. I know you are trying hard to get me to understand you. I really want to understand you. So, how about if you try to talk a little slower and take your time. I will try to listen harder.").

If these strategies do not work, other approaches must be used to understand the person's method of communicating. This may include having an advocate or someone who knows the person well present during questioning and proceedings. An advocate or person close to the individual can help the person understand what is being asked and help others interpret the answers. In using an advocate or other familiar person, attorneys and law enforcement agents should discuss the overall situation and questions with the advocate before questioning begins so that the person can think about how to translate information into concrete, understandable terms for the person with a cognitive disability.

Staying Focused and Calm

Like everyone else, people with cognitive disabilities may associate a question with a previous event that appears to be unrelated. In such instances, it may be helpful to link the association with the question by responding, "That's interesting. How does that relate to (question content)?" Other possible responses include suggesting that such topics be discussed at the end of the interview, taking a break from the interview and letting the person talk, and redirecting the person to the question.

Sometimes people become disruptive or behave inappropriately because they are bored, scared, angry, sad, worried about a loved one who has been hurt, or reminded by the current situation of an unpleasant past experience. If this occurs possible approaches include:

- Redirect the person back to the question in a firm and polite manner.
- Smile, use words of encouragement, pay close attention to the person, and answer questions.
- Ask if the person needs a break.
- Ask whether the person wants to answer the question or go on to the next.
- If the individual poses a physical danger to anyone, terminate the interview and try again later.

Other responses that may be problematic include a response that is irrelevant or inadequate. Options include rephrasing the question, using an alternative format such as pictures, or bringing in someone close to the person to help interpret what is being said.

Responding to a Crime Victim

When a person with a cognitive disability has been a victim of a crime, that person may behave in ways that are mistakenly attributed to their disability. They may be fearful, depressed, aggressive, withdrawn, acting out, or self-destructive. The person may not have the language skills or vocabulary to report an incident or to be viewed as a reliable witness. Concessions must be made by law enforcement personnel, attorneys, and judges to understand the victim's method of communication. An advocate or someone close to the person may be needed to help the victim understand what is being asked during the investigation. Articulation difficulties may require a speech therapist or someone close to the person to "interpret" the person's statement or testimony.

Many adults with cognitive disabilities have a high need to be accepted. If the perpetrator offered friendship or attention, it may have been hard to say no. As a result, the victim may have ended up in an exploitative or abusive relationship that he/she perceived as friendship. When talking to or questioning the victim, the interviewer needs to assess if this is the case. Under such circumstance, the appropriate authorities should be notified.

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Attaining HUMAN RIGHTS, CIVIL RIGHTS, *and* CRIMINAL JUSTICE *for People with* **Fetal Alcohol Syndrome**

BY ANN STREISSGUTH, PH.D.

At a time in history when many people with disabilities are demanding their rights to be fully participating members of their communities, there is another group of people with disabilities who are demanding to be identified. At a time when people with disabilities are trying desperately to rise above their disabilities and be recognized for their basic humanity, people with Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), and other prenatal effects of alcohol are still struggling to be understood for the disabilities they do have. These disabilities are seldom recognized, seldom treated effectively, and seldom connected to service dollars. People with FAS/FAE have a somewhat "hidden" disability — not hidden from themselves, as they experience their disabilities all too acutely. Rather, their disabilities are "hidden" from those who may perceive them to be physically and sensorially intact, and thus fail to recognize their disabilities.

Growing up without benefit of a diagnosis and without an obvious disability means that this group of people with disabilities has never had to fight for inclusion in society; they are considered to be already there (marginally).

People with FAS and FAE have subtle birth defects of the brain. The brain is the organ of the body most vulnerable to the prenatal effects of alcohol. Children and adults can experience subtle brain dysfunction from prenatal alcohol exposure even without the characteristic growth deficiency and facial and physical anomalies associated with FAS in the prepubertal years. The central nervous system (CNS) dysfunction associated with prenatal alcohol exposure (also called Alcohol-Related Neurodevelopmental Disorders or ARND) can cause learning deficiencies, attention and memory difficulties, language, developmental, and motor delays, and problems with organization, speed of information processing and response modulation. These CNS dysfunctions impact social and behavioral interactions, judgment, task persistence and eventually employment and independent living as those affected reach adulthood.

As these problems can have other causes, knowledge that the child had significant alcohol exposure before birth, or that the child's mother had an alcohol problem, or was a regular or binge drinker around the time of pregnancy, is essential in proper identification of this disability. Due to the complexity of linking prenatal alcohol history with subtle CNS dysfunctions, particularly in the absence of clear physical and sensory disability, most children and adults with ARND probably go through life undiagnosed. At this time, there are no biological markers for FAS or FAE, so the determination lies in the skill of the clinician. Yet, this disorder is not uncommon. A recently published epidemiologic study revealed that the prevalence of FAS and ARND was nearly 1 per 100.

Growing up without benefit of a diagnosis and without an obvious disability means that this group of people with disabilities has never had to fight for inclusion in society; they are considered to be already there (marginally). They have never had to fight for "service brokerage"; they have often never had services. They have never had to fight for "individualized funding"; they have often never had funding. Because they are seldom identified, they are seldom counted. When they are not counted, they are not included in master plans. When they are not included in master plans, their needs are not studied. Because they have not been studied, we as a society do not know how to help them.

This is probably what we have been doing for as long as pregnant women have been drinking. We have been treating their children as though their disabilities didn't exist because they weren't obvious. We've been expecting that they would be able to function normally if they just tried harder and applied themselves.

Finally, a large scale study of over 400 people with FAS and FAE, who ranged in age from 6 to 51 years, has been carried out. This new study has clear implications for the human rights, civil rights, and criminal justice of people with FAS/FAE across the lifespan. This study reveals how people with FAS/FAE are inadvertently the treatment failures of the very institutions set up to help people. In part this happens because people with FAS/FAE are often not identified as having disabilities. It also happens as a result of the pervasive belief that they should benefit from the same interventions as people with other

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disabilities — that somehow interventions should be generic.

The construct of "generic" programming has doomed any efforts to-date to develop specialized vocational training programs for this underserved population of people with disabilities. Obviously, people who are blind need different programming from those who are deaf. We know that because we know how to measure blindness and deafness. In contrast, people with FAS/FAE are seldom identified and no model plans have been developed for their particular set of strengths and weaknesses. As a result, when they grow up they are often given more independence than they can handle. They are drowning in independence. Who will toss them a lifeline? Who will help them learn to swim? Who will stave off the circling sharks? Who will put them in their budget and help them manage their lives so that they, too, can have the opportunity to become the best that they can be, accomplish meaningful work, contribute meaningfully to society, and live in fellowship with others?

Let's talk about inclusion and how it relates to the human rights, civil rights, and criminal justice of people who, through no fault of their own, are born with subtle birth defects of the brain.

- Are people with FAS and ARND automatically included in therapeutic day care programs? No, only 10% of those we studied had been.
- Did they attend Headstart or other preschools? No, only 28% had.
- Did they not meet criteria for early or remedial programming because their delays in development weren't obvious? Or because their families did not enroll them? Or because they did not have functional families?

We don't know the answers to these questions. We do know that people with FAS and ARND have at least one parent — their mother — who abused alcohol; that 72% were either physically or sexually abused; and 80% were not raised primarily by their biological parents. We might ask not only what our communities are doing to protect these children, but also what we are doing to help their dysfunctional families. For example, alcohol treatment beds for women, advocacy programs for mothers at high-risk for alcohol and drug abuse, and free family planning are community solutions that help children by helping families. Preventing more children from being born with alcohol-related birth defects helps us all.

People with FAS and FAE appear on both sides of the criminal justice system. They are both victims of crimes and perpetrators of crimes. ...In both contexts, awareness of their brain dysfunction can facilitate appropriate and effective interventions.

What about inclusion in the school system? Is it really appropriate "inclusion" in society if you are suspended, expelled, or drop out of school? Overall about 12% of children and 60% of adolescents with FAS/FAE that we had studied experienced these major school disruptions. Both academic and behavioral problems were cited as causes. In effect, when this happens, the school and the parents are not working as a team and the child and the community suffer the consequences. Not being in school increases an adolescent's risk of getting in trouble with the law, as were 60% of the adolescents and adults with FAS/FAE that we studied. Alcohol and drug problems (experienced by 30% of our adolescents and 45% of our adults with FAS/FAE) are also risk factors for experiencing trouble with the law.

People with FAS and FAE appear on both sides of the criminal justice system. They are both victims of crimes and perpetrators of crimes. Their crimes are often unintentional or unduly influenced by companions. In both contexts, awareness of their diagnosis and understanding of their brain dysfunction can facilitate appropriate and effective interventions. Difficulty in understanding consequences and in generalizing from past experience are characteristics that put people with FAS/FAE at risk for trouble with the law. Appropriate pre-sentence investigations involving other family members are especially useful for FAS/FAE detection. Alternate sentencing for remedial and therapeutic services, active remedial interventions, and close after-care supervision with specific attention to appropriate work, safe living, fellowship, and leisure can interrupt a path toward hopelessness, despair, and recidivism.

Many questions need answering, such as why people with disabilities can, in some states, lose their DD (developmental disabilities) support while incarcerated so that they have no appropriate support after release. Such questions concern the human and civil rights and criminal justice of people with disabilities who have FAS/FAE. But they concern us all when people with unrecognized disabilities inadvertently and repeatedly end up in the juvenile and criminal justice systems as a result of inadequate supervision and support services, as well as inappropriate expectations for fully independent behavior.

Little pockets of hope are now emerging around the country for addressing parts of these complex problems. There are now some model programs available to help communities and families organize for FAS/FAE prevention and intervention services. The Carlson Administration of Minnesota and the Minnesota State Legislature mandated almost $7 million new dollars over 2 years for a massive prevention/intervention plan to include:

- a public awareness campaign;
- research on the prevalence and incidence of FAS/FAE;
- statewide expansion of maternal/child substance abuse projects;
- intervention and advocacy for at-risk chemically dependent women;
- a statewide network of regional diagnostic clinics for FAS/FAE; and
- Juvenile Justice Centers to provide 24-hour centralized receiving,

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processing, and intervention facilities for children accused of community delinquency acts, status offenses, or who are alleged to have been victims of abuse or neglect. FAS/FAE will be systematically screened for, evaluated, and taken into consideration in the intervention process.

In Washington State, the legislature has funded the infrastructure for a network of FAS diagnostic and prevention clinics that are community based, and provided $1.5 million dollars for the biennium for two model programs to work with the highest-risk women in the two largest communities. These women are at risk for abusing alcohol and/or drugs during pregnancy, have delivered a baby after receiving little or no prenatal care, and are not effectively served by other community agencies. This award-winning model program (originally called Birth to 3: the Seattle Advocacy Model for Paraprofessional Intervention, more recently termed P-CAP (Parent-Child Assistance Program)), significantly impacts 5 domains: maternal alcohol and drug treatment; abstinence from alcohol and drugs; effective family planning, child well-being; and connection to services. Washington State also has an exceptionally strong family support network, the FAS Family Resource Institute, which not only supports families but also advocates for prevention and intervention, and educates the community about FAS/FAE. Parent advocacy has been a powerful force for bringing about greater awareness and understanding of FAS/FAE. And after all, understanding is the engine that powers change.

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The information found in this article is described in further detail in two recently published books: Fetal Alcohol Syndrome: A Guide for Families and Communities by Ann Streissguth, Paul H. Brookes Publishing Co. (phone: 1-800-638-3775); and The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities, edited by Ann Streissguth and Jonathan Kanter, University of Washington Press (phone: 1-800-441-4115). The research described here was funded by the Centers for Disease Control, Grant number R04/CCR008515.

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Individuals with Significant Disabilities Who are Victims of Crime

JAMES K. MCAFEE, THE PENNSYLVANIA STATE UNIVERSITY

Certainly, our social and legal systems do not adequately address the needs of victims of crime. For persons with disabilities, the systems are even less adequate and for persons with significant disabilities, existing systems, concepts, training and recognition are inadequate almost to the point of nonexistence. The failure to develop responses to the needs of victims with significant disabilities is a reflection of a greater failure to recognize that people with disabilities are disproportionately victimized and that the consequences of victimization are complicated almost beyond understanding for persons with significant disabilities. In some cases, complications arise because of lack of knowledge; in others the problem is simple neglect.

> *The failure to develop responses to the needs of victims with significant disabilities is a reflection of a greater failure to recognize that people with disabilities are disproportionately victimized.*

The inadequacies of responses to victimization of people with significant disabilities fall into three general areas: protection, prosecution and treatment. Protection refers to those activities that enhance or diminish an individual's ability to avoid being victimized. Prosecution encompasses activities designed to seek retributional justice. Treatment is the process of assisting the individual with the physical, economic and psychological trauma resulting from victimization. Each of these three general areas includes many specific activities. Following is an overview of the primary problems in each area, illustrations from criminal cases, and some suggestions for improving practice.[1]

PROTECTION

If individuals with disabilities can protect themselves from crime, prosecution and treatment will be unnecessary. Unfortunately, many forces work against development of adequate protection. First is the media, which often trivializes victimization of people with disabilities. For example, an analysis of news accounts of crimes revealed that the media more often uses the term "abuse" for a crime involving assault when the victim has a disability. Similarly, the media applies the term "sexual abuse" to crimes ranging from indecent exposure to rape when the victim has a disability (McAfee, 1998).

In one case, a victim who had significant mental retardation had been repeatedly raped, penetrated with a broom handle and eventually impregnated. In newspaper accounts, she was referred to as a victim of sexual abuse not as a rape victim. These euphemisms result in reduced protection because they moderate the outrage that the public and law enforcement should feel about such crimes. People with disabilities are devalued because the crimes against them are devalued. Adequate protective services are less likely to be developed. Further examples of similar devaluation are well-documented by Sobsey (1994).

The second problem of protection is the disproportionate rates of victimization of people with disabilities. This phenomenon is the result of

(a) personal characteristics - people with disabilities often exhibit cognitive, physical and social attributes that make them easier targets for crime;
(b) living environments - persons with disabilities more often live in low income/high crime areas; and
(c) extended dependency - most individuals with significant disabilities continue to be dependent on caregivers well into adulthood. A significant portion of crimes against people with disabilities is perpetrated by persons who are in a caregiver situation.

Crime accounts are filled with cases involving people with significant disabilities who are repeatedly victimized because of their vulnerabilities. One of the most infamous cases involved a young woman who was repeatedly raped by a caregiver in a private facility. The young woman was deaf, blind, nonverbal and had mental retardation. Thus, she could not identify her attacker. She did not understand the nature of the attack, although she surely felt the pain. In short, she was an easy and safe target for the attacker.

A third element of protection is the lack of self-protection education and training programs for people with disabilities. This omission has been clearly documented for nearly 20 years by Balkin (1981), Luckasson (1992) and Sobsey (1994). Self-protection education for people with cognitive disabilities is especially difficult because

1) the concepts of victimization (e.g. "bad touching") are often abstract;

2) people with disabilities may have learned to depend on others for protection and self-protection requires a reversal of a long term process;

3) curricula for self protection training are not available, or they are inappropriate for people with disabilities,

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[1] Illustrations are derived from actual criminal cases in which a person with a disability was victimized. Although criminal records are generally public information, the names in these illustrations have been changed to protect privacy.

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4) adequate and effective self-protection instruction for people with disabilities requires concrete (so-called "hands on") experiences as training episodes; it is difficult to plan training around issues such as credit card fraud, assault, and property theft that is realistic enough to be generalized; and

5) it is rare to encounter professionals who are knowledgeable about both victimization and disabilities who can design effective programs.

What can be done to enhance protection? Several specific actions could go a long way toward improving the situation.

➤ **Education of the media.** Victimization of people with disabilities must be portrayed as serious crimes with the same disturbing and specific language used for crimes against people without disabilities. Media personnel should be called to account when they use terms that gloss over or sanitize the crime. Letters to the editor are often powerful agents of change.

➤ **Analyze the specific environment of people with disabilities to identify risk factors.** Among the questions that individuals with disabilities, family members and professionals must ask are:
- Is the neighborhood a high crime area?
- Is there an alternative living site?
- Are there specific risks in the area (i.e. unlighted parking areas, drug trade)?
- Does the route to work present any special risks?
- Do any of the individual's activities (work, recreation, etc.) present additional risks? For example, does the individual carry money or valuable goods?

> *Victimization of people with disabilities must be portrayed as serious crimes with the same disturbing and specific language used for crimes against people without disabilities.*

➤ **Educate persons with disabilities, their families and their caregivers.** This education must be specifically designed for the individual. Conceptual and global curricula directed at avoiding victimization are not likely to be translated into behaviors that reduce risk in the individual's specific circumstance. One such program is being evaluated in Central Pennsylvania (McAfee, 1996).

Adolescents and young adults with mild to significant mental retardation who are undergoing transition to independence and semi-independence are enrolled in safety training in which dangerous activities, events and locations are identified. Students participate in simulations in which they are the targets of crime. They are taught specific locations and persons to avoid. In order to measure and promote generalization and with their concurrence, during the course of the transition activities (at work, during recreation, and at home), they are targeted for a crime by a person unknown to them. Crimes range from telephone credit card fraud to solicitation for sex. Their responses are recorded and they are later informed that the incident was staged. If their response was inappropriate, reteaching occurs.

During the three years of the program, several participants have been intended victims of real crimes. In all but one case, the intended victim successfully avoided the crime by applying the behaviors learned in the simulations.

PROSECUTION

Clearly, protection is the most important element of victimization efforts. Prosecution efforts can be divided into at least 16 subtopics. A brief description of each follows.

1. *Self-recognition of victimization.* Does the individual recognize that he/she has been victimized?

2. *Awareness of caregivers.* Do caregivers recognize that the individual has been victimized?

3. *Reporting of crime.* Can the individual with a disability or caregivers report the crime? Do they know how to preserve evidence? Do they know how to contact police?

4. *Police awareness, knowledge and attitudes.* Do the police officers receiving the report have enough awareness of disabilities that they can take a meaningful report? Are the police willing to accept the report? Are the police willing to listen to the individual's story?

5. *Police skill in interviewing persons with disabilities.* Do the police have enough knowledge of interviewing people with disabilities so that they can obtain accurate information? Do they know how to avoid tainting statements made by people with disabilities that may be easily led?

6. *Investigation.* Are the law enforcement authorities interested in pursuing the case? Do they think it is winnable? Do they understand and can they ameliorate the impact of the disability on the investigation? Are they committed to the investigation?

7. *Prosecutors' awareness, training and attitudes.* Is the District Attorney (DA)

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knowledgeable, skillful and willing to prosecute? Is the DA willing to learn about the impact of the disability?

8. *Prosecutors' skills in interviewing and questioning.* Does the DA have the skills to obtain information from the victim that will be useful in court? Does the DA have the skills to question the victim on the stand in a such a way as to bring out the information in a manner meaningful to the jury? Does the DA know how to prepare the victim for cross-examination?

9. *The defense attorney's skills and knowledge.* What does the defense attorney know about the disability and its impact on the victim? Has the defense employed expert witnesses to undermine the competency of the victim to testify?

10. *Special statutes.* Are there special statutes designed to protect people with disabilities that might impinge upon prosecution? For example, many states have statutes criminalizing sexual relations with a person who has mental retardation. How does such a statute affect a prosecution in which both the plaintiff and defendant have mental retardation?

11. *Legal constraints/supports for testimony of people with disabilities.* Are there statutory limitations on the testimony of the victim with a disability (i.e., competency to testify laws)? Are there accommodations for testimony that are statutorily provided (e.g., interpreters)?

12. *Courtroom conditions.* Does the courtroom present any barriers to the victim?

13. *The judge's knowledge, attitudes and skills.* Is the judge knowledgeable, skillful and willing to prosecute? Is the judge willing to learn about the impact of the disability? Is the judge willing to provide some latitude in the trial to accommodate the disability?

14. *The composition of and charge to the jury.* What is the nature of the jury? Are they likely to be accepting of the victim with a disability? Has the judge provided any special instructions related to the disability?

15. *The skills of expert witnesses.* Are there expert witnesses? What are their qualifications? Can they assist in the prosecution? Are there experts for the defense who will testify about the victim's disability?

16. *Appeal.* Does the victim, the family and the prosecutorial team have the strength to undergo the almost inevitable appeal?

It is not practical to address each of these elements extensively here. Therefore, illustrative cases, incidents and practices will be presented to highlight the most important issues. Individuals seeking more information should obtain a copy of a manuscript in progress, which will be submitted for publication in 1999.

An incident that illustrates much of the difficulty in prosecuting a case in which the victim is an individual with a significant cognitive disability took place and continues to unfold in Pennsylvania. A 21-year old woman with down syndrome (Nikki) was raped by a 21-year old neighbor in May of 1994. It was not until September of 1994 that the incident was reported to police. The long delay illustrates some of the problems of reporting encountered by individuals with disabilities and their caregivers. At the time of the incident, Nikki did not know how to report the events to her family. Infrequently over the next months, she told her parents, "The boy bothered me." Her parents assumed that this was a continuation of occasional taunts she had endured and counseled her to ignore him because he was ignorant.

> *Euphemisms put forth by the media to describe assaults when the victim has a disability result in reduced protection because they moderate the outrage that the public and law enforcement should feel about such crimes. People with disabilities are devalued because the crimes against them are devalued.*

Nikki's reactions to the assault grew increasingly severe and parents, friends and neighbors began to notice significant changes in her behavior. She was no longer outgoing. She no longer rode her bicycle proudly around the neighborhood and she began to relate details of the assault to others, although in a disjointed and confusing manner. Nikki related significant details to a neighbor who reported them to the parents and then to the police. Fortunately, the officers assigned to the case took the time to learn about Nikki's disabilities, her communication style and her history. One of the officers assigned to the case is the parent of a child with a disability. His understanding and dedication were invaluable to the prosecution.

At this point Nikki and her family, through a series of fortuitous circumstances, had overcome the first five elements of the prosecutorial system. Nikki had made a successful (but delayed report); her family understood the report; the police actively pursued the case; and at least one officer was knowledgeable enough to continue the investigation and obtain consistent information through interviews. The Assistant District Attorney assigned to the case had no knowledge of down syndrome or mental retardation. However, she immediately sought the assistance of an expert who provided her with reading material and direct instruction about down syndrome, mental retardation, communication with people

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with mental retardation, and the likely impact of Nikki's disabilities on the investigation. This relationship lasted throughout the investigation and prosecution.

Nikki's case had now proceeded through the first eight elements of prosecution. The law enforcement authorities began to believe the case was winnable. The district attorney was more than willing to learn about the impact of the disability and how to prepare for the courtroom, and the DA had a consistent source of guidance from an disability expert.

The defense attorney did not take the time to learn about Nikki's disability and its impact on her testimony. Instead, he attempted to portray her as incompetent to testify merely on the basis of her mental retardation. Two competency hearings resulted in a ruling that Nikki was competent to testify, although the judge stated that his decision to find Nikki competent was a very close call. Thus, Nikki had overcome three more elements of the prosecutorial system. The defense attorney apparently underestimated her ability. Nikki was found to be competent and no special statutes that would limit her rights were applicable.

Finally, Nikki's day in court arrived. Again the defense attorney underestimated her testimony, which was often disjointed when she was confronted with unfamiliar terminology or abstract or compound questions. When left to relate the incident in her own words, Nikki was able to describe the factual details of the rape in sequence. When questioned, she often faltered. The judge permitted some latitude in questioning, and the expert witness who had worked on the case was questioned at length about Nikki's mode of communication, the apparent contradictions in her testimony, and his evaluation of Nikki's ability to testify truthfully and factually. The DA used all of the knowledge she had acquired and deftly handled Nikki's difficulties. The judge occasionally intervened to gain an understanding of Nikki's testimony that would not be tainted by the partisan tactics of the defense and prosecution.

Advocates and professionals in the disabilities field must learn about victims' assistance. Victims' assistance providers must learn about disabilities and the impact of disabilities on victimization.

Initially, the jury was disinterested. However, as the trial proceeded, they were obviously struck by Nikki's emotions and her testimony. Nikki gave appropriate testimony, the judge respected her and attempted to accommodate her needs and the jury listened. In the end, Nikki's assailant was convicted and sentenced. Two years later, he won a new trial on appeal. His appeal was predicated on the assertion that the judge had afforded Nikki and the prosecution too much leeway. The case is pending.

Nikki's case illustrates how the prosecutorial system can work for a person with disabilities. It also illustrates the complexity and the occasions for mistakes. At each point, a less caring and poorly prepared team would have faltered. It is perhaps most important to note that Nikki's case was the first successful prosecution of its kind in the large metropolitan area in which it occurred. Similar cases are now being pursued with increased vigor. However, other cases languish because the tools for prosecution do not exist.

A case involving a young woman who is nonverbal and who has profound mental retardation illustrates the limits of prosecution. In this case, the woman was apparently sexually assaulted at a community residential program. Medical evidence indicates that someone had sexual intercourse with her during her stay in the residence. Because she is unable to give testimony and because no other physical evidence exists, the police and the prosecutor are unwilling to pursue the case. The parent cannot even secure an attorney to file a civil suit because they view the case as unwinnable. In fact, they can't even identify who should be the defendant.

TREATMENT

The final major aspect of inquiry relative to victims with disabilities is treatment. When an individual with a disability is the victim of a violent or intrusive crime, the aftermath is even more complicated, frustrating and damaging than when the victim does not have a disability. There are a number of reasons for this.

1. Individuals with cognitive disabilities may have difficulty understanding the crime, the potential impact and their own responses.

2. Individuals with disabilities who have been in dependent situations are not likely to have developed the coping strategies that others in more independent situations have. They are more likely to look to others to "fix the damage."

3. For individuals with significant disabilities, especially those who are nonverbal, naive professionals and caregivers are likely to assume that because the individuals cannot express their feelings, fears and trauma, they don't experience the same depth of trauma as others.

4. Traditional kinds of victims' assistance are likely to be ineffective "Talk" therapy is especially inappropriate for individuals who have limited verbal proficiency.

5. There are few victims' assistance professionals who are experienced with or who have developed appropriate interventions for persons with disabilities. This is especially true where the disability affects communication.

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Should the Death Penalty Apply to Persons with Cognitive Disabilities: The States must Decide

BY BARBARA E. RANSOM, ESQ.
AND DAWN SUTTON, ESQ.
National Advisory Group for Justice

Of the thirty-eight states that authorize the ultimate punishment for offenses that are classified by law as capital, twelve now prohibit the imposition of the death penalty on persons with cognitive disabilities: Arkansas, Colorado, Georgia, Indiana, Kansas, Kentucky, Maryland, Nebraska, New Mexico, New York, Tennessee and Washington. Although the federal government imposes the death penalty for certain offenses, the Congress has passed two laws that specifically prohibit the execution of persons with mental retardation: the Omnibus Drug Initiative Act (1988) and the Federal Death Penalty Act (1994).

The adoption by twelve states and the federal government of legislation that exempts the death penalty for persons with mental retardation is an appropriate affirmation that defendants with mental retardation should not be considered sufficiently culpable to be executed for a criminal act that carries the ultimate penalty. In 1989, Georgia became the first state in the Union to exempt persons with mental retardation from the death penalty. The Georgia legislation specifically mandates that if the defendant is found to be guilty but have mental retardation, the death penalty shall not be imposed; instead, the court shall sentence the defendant to life imprisonment.

The enactment of such legislation generally raises issues regarding the retroactivity of any legislation prohibiting the execution of persons with mental retardation. The Georgia statute contained express language limiting the applicability of the exemption to cases commencing after the legislation's enactment. Nonetheless, litigation immediately arose challenging the retroactivity of the statute (Fleming v. Zant).

The defendant in Fleming argued that his sentence of death more than ten years prior to the enactment of Georgia's exemption legislation violated the Eighth Amendment's guarantee against cruel and unusual punishment. He alleged that newly discovered evidence demonstrating that he had mental retardation at the time of the crime must be considered to determine if his death sentence should be overturned. In concluding that the exemption legislation must be given retroactive application, the Georgia Court reasoned that the enactment of the prohibition showed that the people of Georgia regarded the execution of persons with mental retardation to be cruel and unusual punishment. The Court said that the prohibition against the execution of these individuals would apply, therefore, no matter when the person was sentenced to death and that a retroactive application was necessary to ensure a just application of the law.

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Nebraska, the most recent state to adopt the exemption legislation, has statutory language clearly indicating that its law will be given retroactive effect. In fact, Nebraska's bill, LB 1266, affects inmates currently on death row as well as individuals convicted of first degree murder after the bill becomes law. Nebraska's legislation was implemented only with a concerted effort of concerned lawmakers. Some Nebraska legislators felt that a retroactive application of the exemption laws would result in additional delays in death penalty cases. The legislation's proponents had the task of persuading various state officials that Nebraska law did not contain sufficient safeguards to prevent people with mental retardation from being unfairly executed since the State's Attorney General represented that no person with mental retardation had ever been executed in the state. Currently, Nebraska state law prohibits the execution of someone eighteen years of age or younger, as well as someone with mental retardation. The state senators appear to make these distinctions because they have concluded that the mental capacity of these individuals makes it difficult for them to know the right or wrong of their actions.

These statutes are a rejection of Penry v. Lynaugh, a decision in which the Supreme Court refused to categorically prohibit the imposition of the death penalty for offenders with mental retardation. In 1986 Johnny Paul Penry was convicted of the brutal rape and murder of a woman in Livingston, Texas. Despite a myriad of pre-trial expert testimony that the twenty-two-year-old "Penry had the mental age of a six and one-half-year-old and had been diag-

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Should the Death Penalty Apply to Persons with Cognitive Disabilities: The States Must Decide

Continued from page 25

nosed with organic brain damage," the State of Texas insisted that he was competent to stand trial. The jury rejected the insanity defense based on Penry's mental capacity, found him guilty of capital murder and sentenced him to death.

Penry appealed his sentence to the U.S. Supreme Court, arguing that the jury was never allowed to consider the mitigating evidence of his disability during the sentencing phase of trial, and that the imposition of the death penalty in his case would be cruel and unusual punishment. A majority of the Supreme Court held that the prohibition against cruel and unusual punishment embodied in the Eighth Amendment does not apply to the execution of capital offenders with mental retardation. The high court reasoned that

1. mental retardation is a blurry concept which serves as an inappropriate basis for establishing a sweeping death penalty prohibition, and
2. no societal consensus existed which would justify exempting an entire class of individuals from the state's execution power.

The high court's decision went against the well-established and long-held moral precept of Anglo-American jurisprudence. Common law prohibits the execution of persons without the mental capacity to commit a capital crime knowingly. Ironically, Penry quite possibly would have escaped the death penalty had he been savvy enough to have pleaded temporary insanity. With the decision from the Supreme Court, the case was sent back to the lower court for reconsideration of the death penalty phase by a jury that would take the mitigating factors of his disability into consideration in determining whether or not to sentence Penry to death. Unfortunately, Johnny Lee Penry's trial was in Texas, the state that has executed more people than any other state and more people than are executed in most countries. The jury again sentenced him to death. In 1995, the Court of Criminal Appeals of Texas affirmed the decision of the lower court that "assessed punishment by death." Mr. Penry's execution has been stayed since May 13, 1998 as he awaits further instruction on his execution from Texas officials. (For additional details on the Penry case, see the article beginning on page 28.)

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Mental retardation, with its concomitant limitations in cognitive function and adaptive behavior, must be recognized as a characteristic that sets an accused with a developmental disability apart from other death-eligible accused persons.

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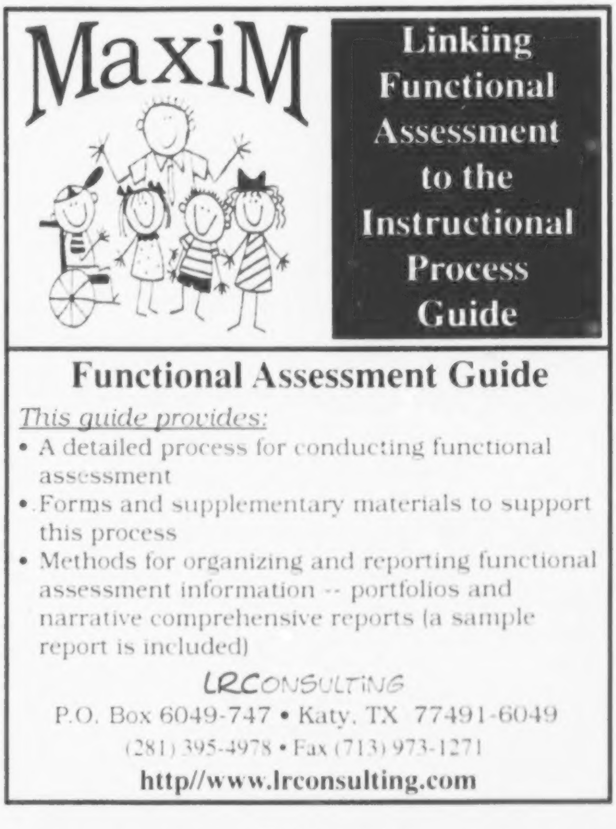
In capital punishment cases, courts must not focus exclusively on the victim and on the heinousness of the crime to the detriment of the defendant with mental retardation who may also be a victim. Mental retardation, with its concomitant limitations in cognitive function and adaptive behavior, must be recognized as a characteristic that sets an accused with a developmental disability apart from other death-eligible accused persons. The enactment of similar exemption legislation in other states will define the societal consensus against executing persons who do not have the cognitive ability to understand the consequences of their actions. Such a response by the states may inspire the Supreme Court to revisit its decision in Penry. This standard of decency that prohibits the ultimate punishment for persons with disabilities as cruel and unusual, therefore, has been left to the determination of the twenty-six states that continue to allow for their execution.

Barbara E. Ransom and Dawn Sutton are Attorneys with the Public Interest Law Center of Philadelphia. They may be reached at 215-627-7100.



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From the Executive Director

Continued from page 3

blue and his face was pale. An ambulance was called.

David was pronounced dead upon arrival at the emergency room. The diagnosis on David's hospital admission form and death certificate read, "seizure respiratory arrest followed by cardiac arrest." The institution's Risk Management Committee found that "any allegation of physical abuse/neglect is unconfirmed."[1]

This story would have ended here if David's parents hadn't been courageous enough to ask questions and pursue legal claims on David's behalf. The story would have gone untold if Amy McCart, a Masters of Science student at the University Kansas hadn't chosen to tell David's story as her masters thesis. Ms. McCart's paper tells the story of a loving, close knit family; of a boy, who grew into a man who loved to sing and go to church, was interested in trains and sewing machines and had strong, enduring relationships with friends and family. It also tells the story of a long history of injuries, starting soon after David moved to Winfield State Hospital.

Between 1983 and 1989, David sustained 389 documented injuries. These included a broken hand, injuries to both elbows that required surgery, a fractured arm, and a spiral fracture of his femur caused by a staff person grabbing and pulling on his leg during a restraint procedure. In 1986, David was injured 55 times and restrained 213 times for a total of over 831 hours. In 1987, he was injured 58 times and restrained 294 times. In 1988, he was injured 70 times and spent a total of 97 days in the hospital.

David lived for only ten days in 1989. On each of those days he was injured. Six of these injuries were of unknown origin, two were self inflicted, and two were caused by staff or other residents. David was killed by staff on January 10, 1989. Had he lived another sixteen days, he would have gone home to celebrate his 40th birthday with his family.[2]

> **It is a sad paradox that the individuals who have the most significant disabilities are the most likely to be placed in environments that directly produce the types of behaviors for which restraints and other aversive procedures are used.**

There has been much controversy lately about highly challenged research out of California that seemed to suggest that institutions were safer places to live than community settings. In the past, when someone would speak to me of the dangers of living in the community I would have said, "We know how to keep people safe - if it is our goal to make sure no one gets into a stranger's car, has unprotected sex or is swindled out of money we could keep people in institutions. The problem is, it's not a life anyone would choose for him/herself or for a loved one." The work of the team of reporters from the *Hartford Courant* has caused me to rethink my position and must cause us to intensify our efforts to close every last institution door. Not only are people's lives made empty by virtue of being institutionalized, their very existence is threatened.

It is a sad paradox that the individuals who have the most significant disabilities are the most likely to be placed in environments that directly produce the types of behaviors for which restraints and other aversive procedures are used.[3] In other words, the sad reality is, the more people dislike living in an institutional setting and having every aspect of their lives controlled, the more likely they are to attempt to protest against such treatment. The more demonstrative their protest, the more likely it is that their behavior will be viewed as an expression of their continued need for institutionalization and the less likely it is that their protest will be heard.

Just as the names on the Vietnam Memorial in Washington only hint at the suffering that was endured, so read the names, dates, and one-line explanations that make up the data base of deaths assembled by the *Hartford Courant* team. But within the lines of information on the spreadsheet, there are hints at the true story - a person killed because he refused to go to the library, another because he was running across a play yard, one after he was denied access to the bathroom, another because she wouldn't go to her day program.

When will we realize that when you deny an individual basic respect and freedoms, he or she is given little choice but to rebel? When will we learn to interpret such rebellion as an adaptive response toward an inhumane environment? When will we figure out that dangerous or disruptive behavior can be reduced by making people's lives better - by enhancing, rather than sacrificing self-esteem, relationships with others, and human dignity?

TASH applauds Dave Altimari, Eric Weiss, the other *Hartford Courant* reporters that worked on this story, and the paper's management, for the intensive effort that was required to tell the whole story. The series in the *Hartford Courant* gives voice to the unheard protest of those individuals who are no longer here to fight on their own behalf.

The full series of *Hartford Courant* articles, and all of the data regarding deaths while being restrained is available on the *Hartford Courant's* web site: <www.courant.com>. You can write to the *Hartford Courant* at: 285 Broad Street, Hartford, CT 06115.

References

[1] McCart, A. (1997). The death of David Dahlke: Winfield State Hospital and Training Center. Unpublished paper. Lawrence, KS: Department of Special Education, University of Kansas.

[2] Ibid.

[3] Rioux, M.H. (1988). The language of pain: Perspectives on behaviour management. Downsville, Ontario: The G. Allan Rocher Institute. 17

PONDERING THE EXECUTION OF JOHNNY PAUL PENRY

BY ROBERT PERSKE

▼ ▼ ▼

By the time TASH members read this newsletter, Penry will probably be dead.

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Johnny Paul Penry was scheduled to die in the Huntsville, Texas death chamber on May 13, 1998, but he received a temporary stay of execution. Even so, most Texans look at this interruption as if it were merely a "speed bump" which the state's legal machine must pass over. Most who are "in the know" believe that Penry will be killed very soon.

By the time TASH members read this newsletter, Penry will probably be dead. It will take place approximately five minutes after midnight. (If, by some stroke of luck, he is still alive when this piece is being read . . . well, a letter to the governor of Texas might be in order, voicing an opinion to spare the man's life—or to get on with the killing.) But what does such a demeaning exclusion from society mean to TASH members who fight so courageously for the inclusion of all people with disabilities?

The Penry case provides TASH members with a rich opportunity to ponder and decide what to do about such situations. Here are a few of the salient facts:

- On May 5, 1956, Johnny was born into a world that was incredibly unkind. He was illegitimate. His breech birth was difficult. His 18-year old mother lost so much blood that transfusions were ordered, but her husband (not Johnny's father) ruled them out because of his religious faith. The mother barely survived, suffered a breakdown and went directly to a mental hospital.

- Ten months later, the mother returned home and launched a series of attacks on her son that lasted for ten years — beatings, scaldings, and worse. According to testimony, his left arm was broken several times. Almost every inch of his skin was burnt with cigarettes. He was locked in his room for such long periods they became fouled with his body wastes. As punishment for such incontinence, the mother sometimes made him eat his own feces and drink his urine.

- Johnny's public school career was short-lived and most of his growing years took place in a number of Texas institutions and diagnostic clinics. At age 23, he was discharged to the Livingston community — to an aimless and lonely freedom with no after care or support.

- Did Johnny do the crime? He did. Two months after his discharge, he became attracted to a young woman he met for only a few minutes. A week later, around 9:30 on the morning of October 19, 1979, he rode his bicycle to her house. He struck up a conversation at her door. She saw him as strange. She tried to slam the door on him. He forced himself into the house. She stabbed him in the back with her scissors. He beat her viciously. He stabbed her with the scissors. Then he rode his bicycle home.

The hunger for revenge against Johnny skyrocketed because the victim, Pamela Moseley Carpenter, came from a prominent, well-loved Livingston family. It also didn't help that her brother, Mark Moseley, was a Washington Redskin football player who was honored as the Most Valuable Player of the National Football League.

On June 26, 1989, the U.S. Supreme Court handed down two sharply divided decisions. It voted 5 to 4 that persons with retardation could be executed, but it also voted 5 to 4 that mitigating factors caused by retardation must also be considered.

During the last of two trials, Johnny's numerous IQ tests were paraded before juries. Most of the scores ranged between IQ 43 to 63. One isolated performance IQ did reach 74 — leading a prosecution psychiatrist to tell the jury that this score was Johnny's "personal best" and all of the others were faked. How this testimony and others like it finally overpowered the defense needs close scrutiny by those of us who care about what happens to such defendants.

But the mixed agony in that courtroom needs to be considered, too. For example, I'll never forget the pain on the faces of the family of Pamela Carpenter as they sat through every trial session. The crime was wrong. Pamela never should have been assaulted and killed the way she was.

On the other hand, I will never forget Johnny's short attention span and lack of focus. Once when the prosecutor shouted that he was a "vicious psychopath," Johnny was more interested in a person having a coughing fit in the audience. I'll never forget how witnesses testified about Johnny's misjudgments — always trying to do right things that turned out wrong. I'll never forget how during court recesses, he turned, faced the audience and smiled. Then he looked for one person — just one person who would smile back.

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PONDERING THE EXECUTION OF JOHNNY PAUL PENRY

Continued from page 28

Looking for a Personal or Class Pursuit?

For starters, get your hands on a copy of The Criminal Justice System and Mental Retardation by Conley, Luckasson and Bouthilet (Baltimore: Brookes Publishing Co., 1992). Read pages 246-278. Here you will find the Amicus Curiae brief filed in the U.S. Supreme Court case in Penry v. Lynaugh (1989). This brief was written by James Ellis and Ruth Luckasson on behalf of TASH and ten other national organizations.

For a journalistic overview of Penry's life and trials, find a copy of Unequal Justice? By Perske (Nashville: Abingdon Press, 1991). Read pages 63-81. Then let this initial information take you where it will.

Robert Perske is an author and prison worker. He can be reached at 203-655-4135.

Correspondence and/or comments to Texas State officials regarding the execution of Johnny Paul Penry may be sent to:

Governor George W. Bush, Jr.
P.O. Box 12428, Austin, TX 78711
Phone: 1-800-252-9600, Fax: 1-512-463-1849

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- **Persons with Disabilities Accused of A Crime**
  Presenters will discuss the impact of the criminal justice system on persons with disabilities who are suspected and/or accused of a crime.

THURSDAY, DECEMBER 03, 1998

8:00 AM-9:00 AM
- Due Process Rights for Persons with Cognitive and Communication Disabilities
  Dohn Hoyle, Marsha Katz
- Assisting People with DD Who are Victims of Crime
  James McAfee

9:15 AM-10:15 AM
- Learning to Work with Law Enforcement
  Dianne Wolfe, Dolores Norley
- The DD Offenders Program: An Alternative Sentencing Program
  Suzanne Lustig

10:30 -11:30 AM
- Law Enforcement Training on Developmental Disabilities
  Forrest Fulton
- Defendants with Retardation: Dilemma for Criminal Justice Personnel
  Dolores Norley

11:45-12:45 PM
- Victim Assistance to Crime Victims with Disabilities
  Debbie O'Neill

11:45 -2:00 PM
- The ADA and Reasonable Accommodations for Persons w/ Disabilities in the Criminal Justice Syst
  Frank Laski, James McAfee, Michael Sullivan

1:00 PM-2:00 PM
- Resources for People with Disabilities Who are Sexually Abused
  Leigh Ann Reynolds

2:15 PM-3:15 PM
- Providers & the Justice System: Acting in Your Client's/Student's Best Interest
  Jane Dalen
- Resources for Victims with Disabilities
  Beverly Frantz

FRIDAY, DECEMBER 4, 1998

8:00 AM-9:00 AM
- Safety and Your Rights
  Cherie Tessier, Dale Colin, Connie Rutherford, Michael Raymond, Diana Robishaw
- The 5 Phases of the Criminal Justice System: From Initial Appearance thru the Correctional Sys
  Suzanne Lustig

9:15 AM-10:15 AM
- The Role for Self-Advocates in Ensuring Reasonable Accommodation in the Criminal Justice Syst
  Liz Obermayer

9:15 AM-11:30 AM
- Understanding Violence in the Lives of People w/DD: Reducing the Risks
  Richard Sobsey

10:30 -11:30 AM
- What You Can Do
  Jeri Houchins

11:45-12:45 PM
- Children and Youth with Disabilities as Victims of Crime
  Patricia Sullivan

11:45 -2:00 PM
- Fetal Alcohol Syndrome in Trouble with the Law
  Ann Streissguth, Barbara Wybrecht

1:00 PM-2:00 PM
- Interviewing Techniques that are Successful in Obtaining Information from Persons with DD
  Mary Hayden

2:15 PM-3:15 PM
- Right Rules
  Tom Verkler, Rob Wybrecht
- A Self-Advocate's Story: One Man's Story of Confessing to a Crime He Did Not Commit
  Russell Daniels

SATURDAY, DECEMBER 5, 1998

8:00 AM-9:00 AM
- From the Cradle to the Grave
  Jeri Houchins
- The Police Interrogation Room
  Robert A. Perske

9:15 AM-10:15 AM
- Issues in Assessment, The Death Penalty & Mental Retardation
  William Edwards, Jennifer Johnston, Denis Keyes, Caroline Everington

9:15 AM-11:30 AM
- Advocates and Allies
  Diane Bryen, Lisa Sonneborn, Sharon Potter, Ray Gagne

10:30 -11:30 AM
- Children and Youth with Disabilities as Perpetrators
  Patricia Sullivan

11:45 -12:45 PM
- The Criminal Justice System as a Level of Intervention for Students with Disabilities
  Barbara Ransom
- Fetal Alcohol Syndrome Cradle to the Grave: What it is and Why it Hurts
  Ann Streissguth

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Individuals with Significant Disabilities Who are Victims of Crime

Continued from page 24

What can professionals, advocates and individuals with disabilities do to improve treatment services for victims with disabilities? First, we must begin to systematically examine the impact of criminal victimization on people with disabilities. This can be accomplished through liaison activities with police departments and victims' assistance programs. Case studies, compilation of statistics and systematic analysis of the impact of violent and intrusive crime are especially critical. Second, we must examine the strategies that appear to have been successful. These strategies include both those that are individual (i.e., where a person with a disability has made a successful recovery from the impact of victimization) and systemic (i.e. where a victims' assistance program has adapted to the needs of persons with disabilities).

Third, we must advocate for inclusion in victims' assistance efforts. This advocacy can have both a moral and legal (ADA) basis. Fourth, we must cross train. Advocates and professionals in the disabilities field must learn about victims' assistance. Victims' assistance providers must learn about disabilities and the impact of disabilities on victimization. Finally, we must take what we do know about assisting individuals with disabilities who have experienced trauma and apply it to victims' assistance.

Two cases illustrate some of the ways that people with disabilities who have been victimized can be assisted in their recovery. In Nikki's case, her recovery was marked by concrete events that were designed to restore a sense of safety. Nikki was present when her assailant was handcuffed and sentenced. This concrete event was the first that Nikki was able to understand that he would not harm her again because he was being removed from her environment. Next, the officer who conducted the investigation regularly visited Nikki at her home and at her job. His presence provided concrete evidence of protection. Later, Nikki was given a photo of the officer in uniform to place in her bedroom as a reminder of his presence. Nikki was taught how to make emergency calls to the police. Each of these actions has helped to restore her security.

In another case in which a young man with significant disabilities was assaulted, he underwent systematic desensitization to the crime scene and people with similar physical characteristics to the criminal. He learned to avoid the appearance of vulnerability, which eventually resulted in his ability to return to travelling back and forth to work on public transportation near the place where the crime occurred.

CONCLUSIONS

The vulnerability of people with disabilities to become victims of crime is clear. It has been clear for centuries as young woman with mental retardation were traded and exploited as prostitutes and individuals with disabilities have been defrauded out of inheritances and trust funds. However, it has only been in the past 20 years that we have seen evidence of systematic and legitimate efforts to understand the extent and impact of crime on people with disabilities. Our understanding is still meager, but promising practices are apparent in disparate and isolated pockets of activity. Consolidation, publication and cross-fertilization are desperately needed to move the promising practices into systematic efforts.

To contact the author for additional information about this article or the in-publication report cited above, write: Dr. James McAfee, Penn State University, Department of Educational and School Psychology and Special Education, 211 Cedar University Park, PA 16802; 814-863-8115 (phone); 814 863-1002 (fax); or JQM@ psu.edu (e-mail).

James McAfee is Associate Professor and Professor in Charge of Special Education at the Pennsylvania State University. Dr. McAfee has taught adolescents with behavior disorders and mental retardation. His primary areas of interest and research are special education law, transition, and criminal justice and individuals with disabilities.

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Resources for Further Information

(Excerpted list reprinted with permission of Impact, published by the Institute on Community Integration (UAP) and the Research & Training Center on Community Living, College of Education and Human Development, University of Minnesota, 1997.)

The following resources may be of use to readers seeking more information about persons with developmental disabilities and the justice system. Please contact the distributors for information about costs and ordering. This list was compiled with the assistance of The Arc of the U.S. *Access to Justice National Resource List.*

- **The International Coalition on Abuse and Disability (ICAD).** ICAD maintains a Web site and an associated listserve that helps to link people concerned about issues of abuse and victimization of persons with disabilities. The Web site address is: http://www.quasar.ualberta.ca/ddc/ICAD/icad.html.

- ***Community Services Reporter* (July 1997).** This issue includes articles profiling programs and approaches for offenders with disabilities from around the country, including the new mentoring program offered to parolees with mental disabilities in Texas. Published monthly by the National Association of State Directors of Developmental Disabilities Services, Inc. (NASDDDS). For subscription and other information contact NASDDDS, 703/683-4202.

- ***Draft Report of the Victims of Crime Committee: A Criminal Justice Task Force for Persons with Developmental Disabilities*** (1997). This report contains 69 major initiatives and reforms necessary to the provision of more equal protection under the law for people with developmental disabilities. Available from Arc California, 120 I Street, 2nd Floor, Sacramento, CA 95814, 916/552-6619.

- **PERSPECTIVE Advocacy.** An advocacy and support organization whose mission is "To ensure legal, civil, and human rights of African Americans and African Americans with mental disabilities and their families." Services include its Justice System Program that assists individuals involved in the criminal or juvenile justice systems. For further information contact PERSPECTIVE Advocacy, P.O. Box 50518, Minneapolis, Minnesota 55404, 612/305-6916.

- **The Arc of the U.S.** The Arc has a variety of materials and activities related to people with disabilities in the criminal justice system. Its Web site (http://TheArc.org/ada/crim.html) includes its Access to Justice National Resource List, as well as online versions of The Arc's criminal justice materials. Also online is a chart describing the 31 individuals with mental retardation who have been executed in the U.S. since 1976. The chart address is: http://TheArc.org/depts/dpchart.html. For additional information on materials and activities, contact Leigh Ann Reynolds at 800/433-5255.

- **Defendants, Victims, and Witnesses with Mental Retardation: An Instructional Guide for Judges and Judicial Educators** (1995). This training curriculum for judges includes practical suggestions on accommodating persons with mental retardation during courtroom proceedings. Topics include identifying persons with mental retardation, facilitating courtroom communication, courtroom accommodations, and court referral for community services. The manual also lists referral agencies for each state. Available from National Judicial College, University of Nevada, Reno, Nevada 89557, 800/255-8343.

- **Into the Jury Box: A Disability Accommodation Guide for State Courts** (1994). This publication offers practical suggestions on how to modify each phase of the jury process to increase accessibility for persons with disabilities. Available fromCommission on Mental and Physical Disability Law, 1800 M Street, N.W., Washington, DC 20036, 202/331-2240.

- **The Criminal Justice and Human Service Systems: A Coordination Handbook** (1994). This publication provides information for people working in the human service and criminal justice systems when both systems are involved in the life of a person with a developmental disability. Available from the South Dakota University Affiliated Program, 414 East Clark Street, Vermillion, South Dakota 57069-2390, 800/658-3080.

- **A Passion for Justice** (1995). This videotape features author and advocate Robert Perske. Inspired by his book *Unequal Justice*, the videotape reveals injustices people with developmental disabilities often encounter when falsely accused of committing crimes. Available from Hilltop Productions, 24 Park Place, Suite 24D, Hartford, CT 06106, 203/951-3557.

- **Contacts with People Who Have Mental Retardation: Training Key #353** (in press). This training package developed by the International Association of Chiefs of Police and updated by The Arc is designed for use in training police officers how to interact with persons with mental retardation. Available from The Arc of the U.S., P.O. Box 1047, Arlington, Texas 76004, 817/261-6003.

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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Please Check Appropriate Categories
(not more than three):
( ) Administrator/Adult Services
( ) Administrator/Education
( ) Administrator/Other
( ) Adult Service Provider/Staff
( ) Behavior Specialist
( ) Case Manager
( ) Early Childhood Services
( ) Educator/Teacher
( ) Gov. Personnel (Federal, State, Local)
( ) Interested Individual/Advocate/Friend
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional Public Policy Advocate
( ) Professor/Instructor (College/University)
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
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Anticipated year of completion ______________________________

( ) Add $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
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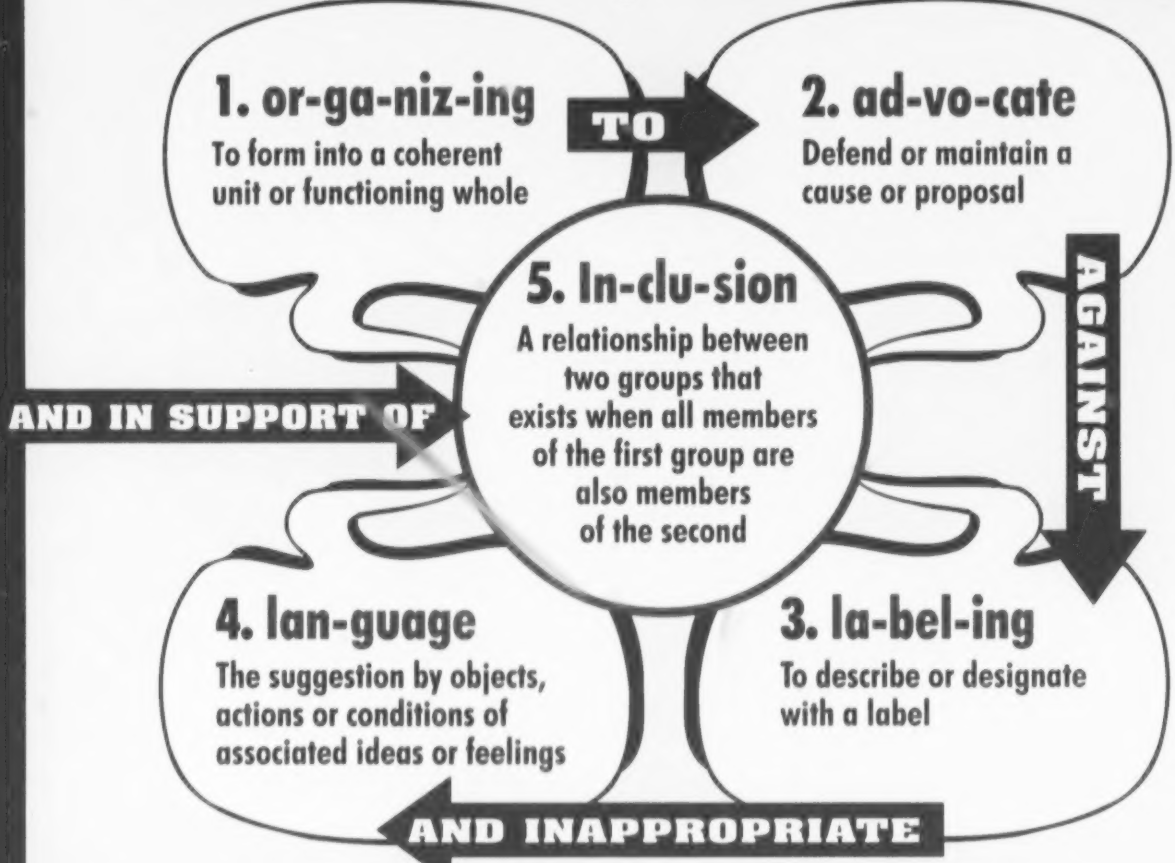
Address Correction Requested

SEPTEMBER 1998

Newsletter

Effects *of* Labeling



1. or-ga-niz-ing
To form into a coherent unit or functioning whole

TO

2. ad-vo-cate
Defend or maintain a cause or proposal

AGAINST

3. la-bel-ing
To describe or designate with a label

AND INAPPROPRIATE

4. lan-guage
The suggestion by objects, actions or conditions of associated ideas or feelings

AND IN SUPPORT OF

5. In-clu-sion
A relationship between two groups that exists when all members of the first group are also members of the second

ALSO INSIDE:
Media Advocacy, Grassroots Organizing, and Speaking Out Against Aversives

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 108 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

More than 55,000 Americans are waiting for organ transplants. One organ and tissue donor can save and improve the lives of up to *50 people*!

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SIGN YOUR DONOR CARD.

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TELL YOUR FAMILY.

For a brochure and donor card, call the Coalition on Donation at 1-888-90-SHARE (1-888-907-4273) or visit the U.S. Department of Health & Human Services Web site http://www.organdonor.gov

(Space for your organization's name)
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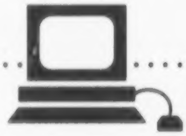
Whom Do I Contact??



- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 1998 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions and advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

From the Executive Director

BY NANCY WEISS

At their recent meeting, the TASH Executive Board discussed the issue of Interest and Action Groups/Committees. As you may remember, all committees used to be called "committees" — it was simple and everyone understood the structure. There were regular committees (groups of people with a common interest who met at the conference or more often) and Operating Committees (groups like the Conference Committee, the Finance Committee etc. that contributed to the work of the Board and the organization). A few years ago, the Board agreed on a new structure. Under the new structure there were "Interest and Action Groups," "Operating Committees," and "Open Project Groups." Many people found the new structure confusing.

The Board felt that the new structure was too complex and discouraged, rather than encouraged, broad participation in the organization. TASH is returning to the original, easy-to-understand structure consisting of only two types of bodies: regular Committees (like Early Childhood, Positive Approaches, etc.) and Operating Committees (examples being the Conference, Finance, and Elections Committee). Any member can start a regular committee by notifying central office of a topic of interest. Regular committees can be on-going or can exist for a specified time period in response to a time-limited concern. They can be chaired by any TASH member. Operating Committees are established by the Board and are chaired or co-chaired by a Board member.

To assure that regular committees have access to the Board and that the Board is kept abreast of committee activities and concerns, a Board member has volunteered to serve as a liaison to each committee.

This year the Board established two new Operating Committees. The first is called the "Anti-Aversives Operating Committee." It is chaired by Linda Rammler. Its purpose is to track the continued use of aversive or restrictive procedures and work for their abolishment. This Operating Committee will work closely with the Positive Approaches Committee. The Anti-Aversives Operating Committee will focus on public policy and political action while the Positive Approaches Committee focuses on best practice in this area.

The Education Committees are similarly structured. There is an IDEA Implementation Operating Committee which focuses on public policy while the regular Education Committee focuses on best practice issues.

The second new Operating Committee is the Awards Committee, chaired by Donna Gilles. This Committee provides an umbrella under which the groups responsible for carrying out award functions will operate.

Please note that all TASH members are invited to participate in any committees in which they have interest. Times and locations for committee meetings will be published in the conference program. Some committees also meet by conference call during the year.

Below is a list of Committees and Operating Committees. Please call (410-828-8274) or e-mail (committees@tash.org) for information on contacting the chair(s) of any committee you are interested in learning more about.

If you have any questions or concerns regarding the changes to the committee structure, please don't hesitate to call me. I look forward to seeing many of you in Seattle!

Operating Committees
- Anti-Aversives
- Chapter
- Conference - Local Planning
- Conference Planning
- Development
- Elections
- Finance
- Governmental Affairs
- IDEA Implementation
- Media
- Membership
- Personnel
- Publications

Committees
- Community Living
- Early Childhood
- Education
- Individuals with Special Health Care Needs
- Integrated Employment and Careers
- International Issues
- Leisure and Recreation
- Marc Gold
- Multicultural Issues
- Paraeducator Issues
- Peace
- Personnel Preparation
- Positive Behavioral Approaches
- Related Services
- Sexual Orientation

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Creating Futures Together

TASH Conference '98

SEATTLE, WASHINGTON

Tentative Conference Agenda

Tuesday, December 1, 1998

8:00 PM - 10:00 PM	Registration Open

Pre-Conference Activities
Wednesday, December 2, 1998

7:30 AM - 8:45 AM	TASH Tech Registration
8:30 AM - 4:30 PM	Club TASH Day Care/Youth Activities
9:00 AM - 4:00 PM	TASH Tech Workshops
9:00 AM - 4:00 PM	TASH Chapter Development and Leadership Training
2:00 PM -8:00 PM	TASH Conference Registration
5:00 PM -7:00 PM	Opening Reception in the TASH Exhibit Hall

Thursday, December 3, 1998

7:30 AM - 1:00 PM	Registration
7:30 AM - 3:00 PM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 3:15 PM	Conference Sessions and Poster Presentations
3:30 PM - 5:30 PM	Plenary Session
5:30 PM -7:00 PM	No-Host Reception

Friday, December 4, 1998

7:30 AM - 11:00 AM	Registration
7:30 AM - 3:00 PM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 3:15 PM	Conference Sessions and Poster Presentations
3:30 PM - 5:30 PM	Plenary Session
5:30 PM - 7:00 PM	TASH Reception (sponsored by WA-TASH Chapter)

Saturday, December 5, 1998

7:30 AM - 9:00 AM	Registration
7:30 AM - 12:00 PM	TASH Exhibit Hall Open
8:30 AM - 1:00 PM	Club TASH Day Care/Youth Activities
8:00 AM - 12:45 PM	Conference Sessions and Poster Presentations

— LOCATION —

Seattle Sheraton Hotel and Towers
(Headquarter Hotel)
1400 Sixth Avenue
Seattle, Washington 98101
Phone: 206-621-9000

Rates:
$123.00 Single • $133.00 Double • $20.00 Additional Person
Room tax is an additional 15.6% per night

Washington State Convention and Trade Center
(Location of Exhibits and Conference Sessions)
800 Convention Place (1 block from Sheraton)
Seattle, WA 98101 • 206-727-2814

ALTERNATE HOTELS

Seattle Hilton
Sixth and University • Seattle, Washington 98111
206-624-0500
Rate $112.00 single/double, plus 15.6% tax
$15.00 extra person
2 1/2 blocks from the Convention Center

Seattle Crown Plaza
1113 6th Avenue • Seattle, WA 98101-3048 • 206-464-1980
Rate: $115.00 single/double , plus 15.6% tax
2 1/2- 3 blocks from Convention Center

— AIRPORT —

Seattle-Tacoma International Airport
16 miles south of Downtown
Average cost for taxi $30, shuttle $18.00, bus $7.50

— AIR TRANSPORTATION —

Southwest Airlines will be the Official Airline for the 1998 TASH Conference

SOUTHWEST AIRLINES

Southwest is offering a 10% discount on most of its already low fares to and from the TASH December 98 Meeting. Call (or have your professional travel agent call) the Southwest Airlines Group Meeting Desk at 1-800-433-5368, Monday – Friday 8:00 AM – 5:00 PM, and Saturday, 9:30 AM – 3:30 PM by no later than November 24, 1998 and refer to I.D. Code K1748 to take advantage of this offer. Call right away as fares are subject to terms and availability.

— GROUND TRANSPORTATION —

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A DIVISION OF HOLLAND AMERICA LINE-WESTOURS

Frequent, fast, convenient Airport Express Service operates between Sea Tac Airport and the Seattle Sheraton and other downtown hotels. Fares are $7.50 one way or $13.00 round trip. (TASH attendees will receive $1.00 off). Please notify Gray Line at least 48 hours in advance if you require wheelchair access. For more details call Gray Line Airport Express at 206-626-6088.

Congratulations

to the following newly elected members of the

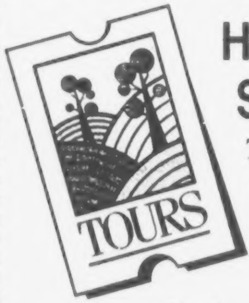
TASH EXECUTIVE BOARD

Jacki Anderson
Douglas Biklen (re-elected)
James Meadours
Jorge Pineda
Patrick Schwarz
Jacque Thousand

* * * * * * * *

We also extend congratulations and best wishes to Linda Bambara, the new Editor of JASH

1998 TASH Annual Conference



HURRY! Space Is Limited!

Take time to experience the taste, sights and sounds that have made Seattle one of the premier convention destinations in the country! Check out one, or both, of these exciting tour events during your stay in Seattle.

Grapes & Hops Tour

Enjoy the scenery of rural Seattle as you travel to the Columbia Winery and Redhook Brewery. First, you tour charming Redhook Brewery. Try several complimentary hearty microbrews, while learning the beer making process and the history of the Redhook Brewery. You'll receive a Redhook Brewery souvenir glass during the tour.

Next, tour the spectacular Columbia Winery. You'll discover Columbia Winery's history and how this winery produces such award-winning wines. After the tour, enjoy complimentary wine tasting - a feast for the senses.

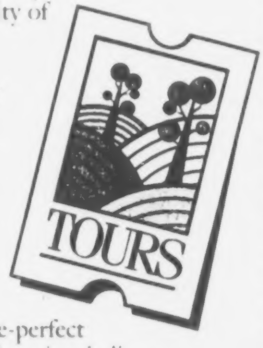
Date: Saturday, December 5th; tour departs at 2:00 PM
Duration: Approximately 5 hours
Cost: $42.00 (includes a box lunch)

Seattle City Tour

You will learn why Seattle has been named one of America's most livable cities! Our friendly and informative tour guide will give historical background on the area, point out interesting landmarks, as well as give insider tips on special shopping and sightseeing areas.

Included in the tour is Freeway Park and the bustling Pike Place Market where Seattleites shop for produce and art. You'll see historic Pioneer Square which was settled in 1852 and is now home to Seattle's top art galleries; the International District, heart of Seattle's Asian community; and the magnificent gothic-style buildings on the 680-acre University of Washington campus.

Next, explore the Hiram Chittenden Locks, the passageway between saltwater and fresh for 78,000 vessels a year. Inspect the fish ladders where thousands of salmon travel upstream to spawn. Visit a local coffee roasting plant and learn all about coffee roasting. Finish your tour at one last stop - Magnolia Bluff neighborhood - north of the city, for picture-perfect views of Elliott Bay and the stunning city skyline.



Date: Sunday, December 6th; tour departs at 9:00 AM
Duration: Approximately 3 hours
Cost: $28.00

GRASSROOTS ORGANIZING

— *Unleash* — THE POWER

BY JOYCE LIPMAN

Who would have believed it? A 5-year Governor's Initiative in Maryland that provides over 64 million state dollars for the Waiting List — when in earlier years we've barely eked out enough money for emergencies and transitioning youth.

The Initiative, which draws down federal matching dollars for a total of $118 million, funds both categories: emergencies and transition. In addition, it funds - completely - the Waiting List for day programs and in-home supports for both children and adults living with their families. It makes a major dent in the intractable Waiting List for residential services. (We hope to stretch the money with creative, nontraditional services.) To help families plan their services and supports, the Initiative includes service coordination. Finally, a cost of living increase for provider agencies, though not as much as we'd hoped, gives these agencies more money for staff salaries. This increase is, of course, important for quality.

How we got from there to here

How did this happen? Well, an election year and a budget surplus didn't hurt. But, primarily, our success is a testimony to what advocacy can do. Although it seemed to, success did not come about because of one year's efforts. This story has had many heroes and heroines over more than 20 years. Some of them work in the developmental disabilities field. Others are family members. And, in recent years, many self-advocates have spoken most eloquently for themselves.

What The Arc of Maryland's 1997-98 Waiting List Campaign did was bring together grassroots activism with careful public policy strategy. As a large membership organization with a history of family/professional partnership, The Arc was particularly suited to providing leadership in such a campaign.

As a Waiting List parent myself, I felt the pressing need to address this issue and had begun organizing families in my own county. After all, politicians respond to numbers. Then, when a friend suggested that we have a county forum for Waiting List families, I suggested that, instead, we needed to bring people together statewide. At the same time, Cristine Marchand, The Arc of Maryland's Executive Director, heard about a Waiting List Conference in another state.

When we saw reports about how The Arc of New Jersey had wrenched an Initiative out of a governor with a conservative agenda, we decided to forge ahead with our own campaign. We began by inviting Paul Potito, Executive Director of The Arc of New Jersey, to speak to our Governmental Affairs Committee. He gave us methodology and lessons learned that we could use and adapt to the situation in Maryland.

So with a $10,000 pot of money designated by our Board of Directors from a bequest, we launched our Campaign. The first thing we did was hire a campaign coordinator to take care of the administrative details that the small Arc of Maryland staff could not accommodate. The coordinator, Susan Dotson, worked with Christine and me to plan our campaign, starting with a kick-off conference for families on the Waiting List, set for September 1997.

Like New Jersey, we reached out to families with a mailing to the entire Waiting List, asking families to join our effort. Along with a parent-to-parent letter from me, the mailing included a fold-over questionnaire with a return address to The Arc. Since we did not have access to the entire Waiting List due to confidentiality, we needed support from the Developmental Disabilities Administration (DDA) to get the letters out. DDA Director Diane Coughlin came through for us, and families received their letters in June 1997.

In response, we heard from nearly 600 families. They all seemed to say, "At last some hope." Many told of desperate situations that had all of us in tears. We were particularly struck by the almost 70-year-old parents who told of losing their support system (three brothers) in one year. The father wrote:

> *"Governor, three times in the past two years, I have been hospitalized with infections. A physician at George Washington Hospital says I need a shoulder replacement, and I suffer from arthritis in my lower back. My wife also is disabled with arthritis in her knee and in her hands. We are growing old. I retired at age 66 after 47 years in the workforce. I served as a paratrooper in the U.S. Army during the Korean conflict. Governor, I am simply tired. . When The Arc personnel speak of ending the waiting list, our hearts sing."*

We worked throughout the summer processing these responses, building a database, and planning the Waiting List Conference. Two of our concerns in considering the needs of Waiting List families were to provide respite care and transportation, as necessary. When we started worrying about expenses, help arrived in the form of a $5,000 grant from The Joseph P Kennedy, Jr. Foundation. Moving forward, we sent a conference registration form to those families who had indicated an interest in the event on their questionnaire.

As September approached, local Arcs also followed through with phone calls to encourage family members to attend. The result was close to 300 attendees, including

Continued on page 7

UNLEASH THE POWER

Continued from page 6

invited public officials and legislators. To emphasize that the Waiting List was about real people, families brought pictures for our "FACES" display as the price for admission. (We used this folding exhibit throughout the Campaign at every major event.)

At the Conference Paul Potito and former Arc of New Jersey President Fred Patterson - a Waiting List dad - presented a powerful recap of their state's Campaign and its eventual success. They energized families and made them begin to hope that this, indeed, could happen in Maryland. The program also included information on new directions in Massachusetts as described by Leo Sarkissian, Executive Director of The Arc of Massachusetts. To tie into the Maryland system, families then heard from Diane Coughlin and from Beatrice Rodgers, Director of the Governor's Office on Individuals with Disabilities - both terrific supporters.

From information to action

We spent the afternoon honing letters to Maryland's Governor, Parris Glendening, legislators and newspaper editors. We defined our message to the media and gathered media profiles from those families who would agree to be interviewed. We planned town meetings and small in-home coffees with legislators to get our message across. Everyone left the Conference ready to move forward.

Alongside the grassroots effort, we joined Maryland's Developmental Disabilities (DD) Council to design the public policy piece. We strategized, lobbied, and planned events with representatives from the DD Council, the Maryland Association of Community Services and the Maryland Disability Law Center.

When we first requested a meeting with Governor Glendening's Administration, we were told that only professionals, not families, should attend. Christine Marchand, believing strongly that our strength lies in families and their stories, stressed the need to bring families. So we went and told our stories.

Sue Dotson with her son Matthew, me with my "sandwich-generation" (baby boomers who have the dual responsibility of caring for adult sons and daughters with disabilities and aging parents) tale of woe, and a woman in crisis who had kidney disease and couldn't get emergency funding each told our stories. And those stories had their effect. Donna Jacobs, the Governor's Deputy Chief of Staff and a wonderful, caring person, heard us and took up our cause. That day was a turning point.

We also invited families representing three age groups to a legislative hearing on unmet needs. But before doing so, Christine worked with DDA to put together a concrete plan delineating numbers of people on the Waiting List, service need, and cost, plus the amount available through the federal match. The plan set out the costs for service coordination and salary enhancement, as well. These carefully described costs impressed the Governor's Director of Finance. We weren't just asking for help. We had done our homework.

The plan, however, represented more than numbers. It set forth five key principles - all later incorporated in the Governor's Initiative.

Principle 1: Eliminate the Day Program Waiting List in two years.

Principle 2: Eliminate the Family Support Services Waiting List in one year.

Principle 3: With DDA's collaboration, the DD Council proposed to use Initiative dollars to fund systems reform services and supports using self-determination principles.

Principle 4: With the support of Service Coordinators, everyone would create a person-centered plan so funding and innovation would go hand-in-hand.

Principle 5: Increase funding for direct care workers to ensure quality.

After we spoke with the Director of Finance, one of our legislators arranged a meeting for us with the Governor's Chief of Staff, Major Riddick. At this point, Mr. Riddick promised to work with us toward an Initiative. We were pretty sure something was forthcoming, but we didn't know what or how much.

While all of this was going on, families were flooding the Govemor's office with mail. We were also writing letters to the editor and getting Waiting List stories in newspapers across the state. Diana Sugg of the *Baltimore Sun* wrote a compelling front page story about a father in his 80s trying after his wife's death to cope with caring for his 46-year-old son alone. We also approached legislators about joining our cause. Many counties across the state held town meetings where panels of families gave legislators glimpses into the fears and frustrations of Waiting List families.

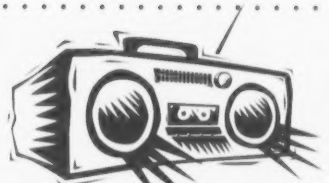
In Montgomery County, where I live, the county government co-sponsored the event, which was attended by close to 300 people. We heard the stories of the elderly father who said he'd rather shoot his son than have him join the homeless contingent under the bridge; the 70+ year-old-mother who had just been diagnosed with terminal cancer and two months to live; and the younger mother who had joined Operation Desert Storm as a respite from caregiving. We also heard, "My son is my best friend," and "My son is the nicest person I know." Overwhelmed, legislators pledged their support.

Other counties planned small coffees where one or a few families invited their own legislators to meet them and learn of their situations. This approach worked best in more rural areas, or where pro-institution legislators were less receptive to Arc-sponsored events.

To keep families updated on what was going on, we (like New Jersey) sent out a bimonthly *Waiting List Watch* newsletter. We included sample letters as well as dates and events of note. In addition, we established an 800 hotline with information and the opportunity for questions and feedback.

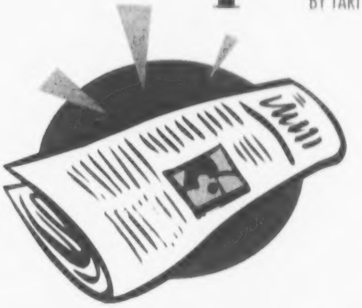
Finally, in January 1998, we were invited to a meeting where Ms. Jacobs', the Governor's Deputy Chief of Staff, informed us that we did, indeed, have an Initiative that came close to what we had requested, though it would stretch over five instead of four years. We were elated! But we had to keep mum for three days until the Governcr announced his Initiative at his press conference. What a challenge. After the announcement, we broke out the champagne. And the reporters came to us. We made the front page of both the *Washington Post* and the

Continued on page 29



Media Advocacy and Empowerment

BY TARI SUSAN HARTMAN



Attitudes about ourselves and others are created and shaped by experiences. Most experiences are firmly rooted in first-hand reality. Others are greatly influenced by positive and negative media images. Media is the most powerful influence of modern society. Negative media images create more of a collective handicap than one's own individual disability.

As the disability community's leading organizations continue their fight(s) for human rights and to sustain hard won victories (TASH, on behalf of IDEA; Not Dead Yet against assisted suicide; ADAPT in support of MiCASA, to name a few), one way to sway public opinion is with strategic long range and sustained media campaigns.

It's critical to start building and renewing relationships with the press on a local and national level. This can start with and be nurtured by one person in your organization dedicated to this responsibility. Through the eyes of reporters who cover disability issues, the general non- disabled public and policy makers come to learn, understand, support and appreciate disability rights, community inclusion, options and pride.

One way to sway public opinion is with strategic long range and sustained media campaigns.

This article introduces some basics. Individuals and organizations establish priorities that will, in turn, determine results. All of us have been led to believe we are "power-less." When it comes to impacting media, that is not true! As people with developmental disabilities, their families and friends become empowered toward full community inclusion and options, we need to deliver messages of truth with dignity, clarity and strength.

It is said every crisis creates an opportunity. Recent negative coverage and backlash triggered by the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA) across the nation has created opportunity for the disability community to activate media advocacy and empowerment.

Media advocacy principles, as outlined in Media Advocacy and Public Health by Lawrence Wallack, Lori Dorfman, David Jernigan and Makani Themba (Sage Publications) include: "Media Advocacy seeks to influence selection of topics by the mass media and shape debate about these topics...(its) purpose is to contribute to the development and implementation of social and policy initiatives that promote health and well-being and are based on principles of social justice...relies on coalition building and community organization for its base of support...seeks to provide community groups with skills to communicate their own story in their own words."

Building Relationships with the Press

Now is the best time to establish and/or build relationships with the press. Like anything in life, including your work to influence policy makers, educators and the general public, relationships are the critical foundation for success. The media is no different. They are just another "system" we are trying to penetrate and influence, to help shatter centuries of negative public opinion and initiate a paradigm shift toward a new reality.

Look at newspaper and magazine articles as an opportunity for inclusion about disability issues. Most articles are a basis for establishing and building relationships. Do articles about legislation, housing, employment, education, business, transportation, or diversity have a potential disability perspective angle or "hook?"

Dust off past articles. Establish a clipping file and and internal media strategy. Designate a media relations

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MEDIA ADVOCACY AND EMPOWERMENT

Continued from page 8

person to contact reporters who interviewed you and colleagues, or who wrote about disability/diversity issues. The designated media person should contact news producers, editors, and reporters when disability and diversity issues appear. Increased contact is a basis for building solid relationships. Give positive and negative feedback (language and content) and background relating to a bigger disability picture. Separate intention from result. Feedback helps establish trust.

Language within an article has a different tone than headlines or photo captions. Specific editors are responsible for these. Unlike reporters who may be savvy with disability semantics, editors don't have opportunities to be educated in terms of language.

One goal is to position your organization as a source to be kept in the files of print and electronic media (TV and radio) for future reference/comment. You can provide accurate information by adding a pro-active, pro-disability spin.

Ten years ago, Jay Mathews (former LA Bureau Chief for the Washington Post) broke the story of Tiffany Callo (a young woman with cerebral palsy fighting for custody of her children) on a national level through a series of articles in the Washington Post. Five years ago, he wrote a book, and credited disability rights attorneys Margaret Jakobson and Deborah Kaplan for the strategy. Relationships pay off for years, even if reporters change media outlets.

"What's in a Name?"

Like other stigmatized minority groups, people with disabilities are in a continuous and evolutionary process of choosing language and semantics they prefer to be used to describe themselves and their experiences. Like other aspects of disability politics, this is not homogenous. There are ideological differences manifest in language usage amongst various factions of disability rights, pride and culture movements.

Sometimes language is merely dismissed as an effort to be politically correct (PC) — a smoke screen to deflect the real issues of a minority people's right to name themselves.

Increasingly many people feel the concept of "PC" is that of "Politically Conscious" as opposed to "Political Correctness." Those involved with people with developmental disabilities clearly prefer People first Language. People First was one of the first self-determination organizations of, by and for people with developmental disabilities that sprung out of the Disability Rights and Independent Living Movements of the 1970s. People first Language is not as much an issue for those involved in the physical and cross-disability rights, culture and pride movements.

Carol Gill is an Assistant Professor and Director of the Chicago Center for Disability Research; Department of Disability and Human Development, University of Illinois at Chicago, a board member of the Society for Disability Studies and a psychotherapist, whose long-term private practice has included people with disabilities in Los Angeles and Chicago. Dr. Gill (and many of her colleagues) has no objection to placing the disability either before or after the person when speaking or writing. However, she objects strongly to those who insist that People First Language is the only proper form. The reasons are based on her academic research, private practice, and experiences as a woman with a disability.

Increasingly, many people feel the concept of "PC" is that of "Politically Conscious" as opposed to "Political Correctness." Those involved with people with developmental disabilities clearly prefer People first language. . . People first Language is not as much an issue for those involved in the physical and cross-disability rights, culture and pride movements.

"I don't mind People first Language, I do mind the insistence on it. My disability is an integral component of who I am — I am incredibly proud to be a disabled woman. As a psychologist, I have listened to hundreds of people with disabilities tell how horrible it has been to have parts of themselves rejected. They have been harmed by messages that suggest they should downplay the disability and play up their personhood - as if the two could be separated."

Disability pride and culture movements affirm that we are who we are with our disability, not in spite of it. Integrating our disabilities in a substantial and fundamental way can lead to improved self esteem. With the exception of the phrase, "people of color," I know of no other examples of placing personhood over gender, age, religion, ethnicity, sexual preference, etc."

Over the past twenty years, many language guidelines have been developed within different segments of the disability community in an attempt to make journalists and mainstream media outlets aware of the destructive, paternalistic and defaming ramifications of their language choices. Several years ago, a survey was conducted by EIN SOF, The Dole Foundation on Employment of People with Disabilities and others with recommendations forwarded to the AP Stylebook. Even though it was appreciated by the Associated Press, some still perceived that action as a PC attempt.

Whatever your language choice, communicate it with reporters covering disability issues. Consciousness raising in terms of language is a long and never-ending process. There is consensus in avoiding terms such as wheelchair-bound or confined, inspirational, brave and courageous, medicalization of the disability experience, such as impaired, afflicted with, victim of and suffers from; and outdated labels such as crippled,

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MEDIA ADVOCACY AND EMPOWERMENT

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lame, moron, deaf and dumb, defective and idiot.

It appears that journalists (and therefore the general public) have adopted the transitions from Negro, to Black, to African-American with more acceptance than they do preferences for disability language. Whether that is due to the consensus of terms within the African-American community, or acceptance of the power of their voice, is open to discussion.

Public Service Announcements (PSAs) and Public Affairs Programming

For any non-profit 501 (c) (3) organization these two avenues are wonderful opportunities to disseminate basic information. Each media market is different. For example, in Southern California organizations must first receive a identification number from the Southern California Broadcasters Association (SCBA #) to qualify (a $35 annual fee) for this type of coverage. To find out if such an organization exists in your part of the nation, contact any public affairs or public service director at any local TV or radio station.

Public Service Announcements (PSAs) and public/community affairs programs appear on radio and TV stations as a responsibility for the station's right to use the public airways. Some stations are located on university campuses. University Affiliated Programs, Disability Studies and Disabled Student Service Centers may have contacts with the station.

PSAs range from 10 to 60 second formats, so check with each specific station. Some stations broadcast in languages others than English and each has its own format (rock, classical, talk, religious, news). Radio PSAs are easier because they don't require costly graphics or slick production. All PSAs must be printed on non-profit organizational letterhead and must arrive at the station 3-4 weeks prior to their usage.

Check with the Public Service Director at the each station before sending PSAs to confirm the length and desired format. Follow-up after you send information. At that time they may tell you if and when they will use your PSA. PSAs can either be generic or event-specific. For event-specific, be certain the content does not mention fund raising, just an announcement for an event that is open to the public.

> **Through the eyes of reporters who cover disability issues, the general non-disabled public and policymakers come to learn, understand, support and appreciate disability rights, community inclusion, options and pride.**

Public affairs programs (sometimes called community affairs) are a great opportunity for more in-depth communication about the organization or a particular current and newsworthy issue. A specific spokesperson should be selected in advance. Call program producers (who are often the Public Affairs Directors) to "pitch" the story and the guest. You should watch and/or listen to the show prior to making the phone call to make sure it is a good match. The better prepared you are, the better your chances for placement and the better the result of the program. Most public affairs interview segments are 15 - 30 minutes and air at non-peak hours, but they are a good opportunity.

Tips on being interviewed

It is perfectly appropriate for you to set the tone and ground rules in terms of language and avoiding condescending camera angles. By lowering the tri-pod or "sticks" or asking the camera person to kneel, the camera will be eye-level with a person using a wheelchair or a person of short stature. Be assertive and remind them not to fix the camera on a sign language interpreter, augmentative communication devise, wheelchair part, guide dog, cane, or fingers reading Braille. Camera persons and reporters are just consumers of mainstream media and therefore hold the same biased beliefs that people with disabilities are just the sum of the above mentioned parts, as opposed to whole and complete human beings.

Most sound bites are 10 - 15 seconds, so make it count. Always begin with the most important information. In the first 10 seconds, a reporter decides if you are a good and dynamic spokesperson or not.

Before the interview, give reporters a press kit and point out pertinent background information, statistics, chronologies and remind them of your preferred language. You can also correct them once you start. Maintain eye contact with the reporter who may be positioned next to the lens of the camera, and try to keep the interview like a conversation.

Don't let the reporter back you into a corner and try to maintain control of the interview with your agenda, and that of our constituency. Don't let a reporter provoke you so you raise your voice, becoming unreasonable. Use analogies, as they paint the big picture for the general public (through the reporter).

Offer (or kindly persist) to write interview questions (to insure quality control, so they don't miss the mark). This is also an opportunity to educate the media about etiquette for communicating with people with disabilities. On camera, this is very important because the comfort level will transcend to the television audience.

Together, we can, and will make a difference. Here's to your own stories, in your own words!

Tari Susan Hartman is President of EIN SOF Communications, a marketing, public relations and production company working exclusively with the disability community. EIN SOF Communications may be contacted by e-mail <EINSOFTSH@aol.com> or phone (310-578-5955).

TASH wishes to acknowledge the generous support of our newest lifetime members

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EQUALITY

BY NANCY BURNS

There's an issue I've not heard talked about in the disability movement. All the discussion about transportation, housing, jobs, and education is great. I personally believe we're STILL at square one with labeling.

I've noticed people sometimes have a real tendency to look at the disability rather than the person. (Hey, don't feel bad, those of us who have a disability do the same thing!) If we could learn to put down the "labels," walk away from them and concentrate on the person, we'd be in a better position to help in a more concrete, positive way. Listening is the most important thing; not just with the physical ear but with the heart, as well. To truly know what a person wants and needs, not what someone else wants for them, is the issue. Then, and only then, can a real difference be made. But how do we truly put down those labels?

If we have to use labels, why not have more generic or general terms than what we have now? Forget about being "mentally retarded," "physically or mentally challenged," "Down syndrome," "mentally ill," "consumer," or "client" and all the rest. Being thought of as a consumer or customer makes me feel like I should be going out and buying a loaf of bread or something. Why can't we be thought of as ordinary, regular people?

As someone who has a disability, I don't want to be thought of or treated like I'm special, stupid, a freak, different, the village idiot, an alien from outer space, a second class citizen or invisible. Treat me with the same amount of respect and consideration you would give to someone else — no matter what. Get to know the person on the inside and not just by the disability. i bet you'll find they are not that much different from you.

■ ■ ■

If we could learn to put down the "labels," walk away from them and concentrate on the person, we'd be in a better position to help in a more concrete, positive way.

■ ■ ■

I attended a meeting with some friends earlier this year. One of the videos they showed was "Willowbrook: The Last Disgrace 25 Years Later" from the *Geraldo Show* that aired on January 6, 1997. That's where I got the idea for this story, and why I wrote the first paragraph. I've been abandoned and hurt by people who didn't care. I've had to live with insensitive labels. I've had people call me mean and rude names. I also have lived in places where I was treated the way you wouldn't think about treating your puppy. I've been judged, looked down on, not given a thought or a chance, betrayed, laughed at. I've been pitied, mistreated, abused, not respected, called names and stared at.

I've heard of some parents abandoning or starving their children. I suppose they did this because of stupidity, fear, or ignorance. I don't know! It's always amazing to me how differently people can see each other. Is this like having two people read the same newspaper story and coming away having two different ideas or interpretations?

What I'm seeing are people who are being denied jobs, housing, transportation, and accessibility because of a disability. I see people having to wear a "label" because they do things differently and have different ways of getting around.

Someone I know once told me that having a disability is only a small part of who I am as a person. She's right. I wish people who give labels could know that. We want to be treated with the same respect as everyone else! If we could do that — treat each other with respect — then there would be the equality everyone deserves. What a concept!

• • •

Treat me with the same amount of respect and consideration you would give to someone else — no matter what. Get to know the person on the inside and not just by the disability. I bet you'll find they are not that much different from you.

• • •

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STATUS AND EFFECTS OF LABELING

BY ANNIE FORTS, NEW HAMPSHIRE

The following interview with Alan Robichaud, Executive Director of the New Hampshire Developmental Disabilities Council, was conducted by Annie Forts on behalf of Community Advocacy Press.

Where does the New Hampshire Developmental Disabilities Council stand on the issue of labeling?

The New Hampshire Developmental Disabilities Council (Council) does not believe it is appropriate to label people. Hopefully, we have learned that all people should be accepted for who they are, with all the talents, skills and imperfections that life deals out. Labeling has always created negative images when applied to people with disabilities, as it always projects the disability rather than a person's gifts and talents.

These negative images then go on to cause society to treat people with disabilities as less than human and worthy only of our charity and pity. There is no room for this way of thinking if we are to successfully advocate for all people to lead happy and healthy lives.

The poster created by the Human Policy Press, entitled: "Label Jars ... Not People" still has an important message for us all and serves as an unpleasant reminder that society still treats people with disabilities differently.

What is the Council doing on the issue of labeling?

The Council does not have a specific initiative on dealing with the issues of labeling. We have worked hard to educate ourselves and others as to the negative impact labeling has on people. Whenever it best serves, individual Council members and staff will respond, through direct conversations, letters to the editor and other means to correct injustices caused by inappropriate labeling.

Additionally, we continue to use a pamphlet which the Council created a few years ago, entitled Choosing Words With Dignity, which we give to newspaper reporters, legislators, community organizations and others as the need and as opportunity arises. This pamphlet was inspired, in part, by the Vermont Developmental Disabilities Council. [The creation of this pamphlet] is a clear reflection that Councils take positive imaging of people with disabilities very seriously.

• • •

Change takes time.

Worthwhile change will

make that time beneficial.

When we take the time

to look inside the person

we will discover the treasures

of each individual.

If we don't care to look,

then we don't care.

• • •

This kind of public education is constant. A one-shot attempt to educate the public or various aspects of it is not effective. "Vigilance is constant," as the saying goes.

Has there been any Council policy statement on labeling?

Specifically, no. The Council has never formally adopted a policy statement on the issue of labeling. However, through our practices, initiatives and recruitment of Council members, we are cautious not to accept proposals or members that do not project a positive, healthy attitude in relating to or about people with disabilities.

We must remember the fields of medicine and human services invented all, or most, of the words that today we find offensive. We must be critical and fight to prevent the constant use of language which people now find offensive. Certainly we must stamp out oppression. But, we cannot condemn the uninformed just because they are using what we once taught them.

Change takes time. Worthwhile change will make that time beneficial. When we take the time to look inside the person we will discover the treasures of each individual. If we don't care to look, then we don't care. When people don't care, then communities don't care. When communities don't care, society doesn't care. When society no longer cares, we have some very serious problems.

Developmental Disabilities Councils across the country are building caring communities. With the help of people with disabilities, their families and neighbors we will continue to educate and welcome the participation of all our citizens in creating healthy communities. Then, maybe then, people will no longer feel a need to use labels on people who were once strangers to them.

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To achieve INCLUSION, COMMUNITY, *and* FREEDOM *for people with disabilities, we must use People first Language*

BY KATHIE SNOW

Who are "the handicapped"... the "disabled"? Society's myths tell us they are:

- people who "suffer" from the "tragedy" of "birth defects";
- paraplegic "heroes" "struggling" to become "normal";
- "victims" of diseases "fighting" to regain their lives;
- categorically..."the disabled, the retarded, the autistic, the blind, the deaf, the learning disabled" and more

Who are they, really?

They are moms and dads and sons and daughters...employees and employers ...scientists... friends and neighbors...movie stars...leaders and followers...students and teachers... they are...people. They are people.

They are people, first.

Are you myopic or do you wear glasses?

Are you cancerous or do you have cancer?

Are you freckled or do you have freckles?

Are you handicapped/disabled or do you have a disability?

People First Language describes what a person HAS, not what a person IS.

People First Language puts the person before the disability.

Disability has been defined as a body function that operates differently.

Contrast that meaning with:

A published origin of "handicap" refers to "hand in cap," a game where winners were penalized or put at a disadvantage. Another theory regarding the origin of the word is that it refers to a person with a disability having to beg on the street with "cap in hand."

> **The difference between the right word and the almost right word is the difference between lightning and the lightning bug.**
>
> • • •
>
> **Mark Twain**

"Handicapped," "Disabled," or "People with Disabilities": Which description is more accurate?

Using "the handicapped," and even "the disabled," usually evokes negative feelings (sadness, pity, fear) and creates a stereotypical perception that people with disabilities are all alike. All people who have brown hair are not alike. All people who have disabilities are not alike.

Many people who have disabilities would never think of themselves as "handicapped."

The disability community is the largest minority group in our country. It includes people of both genders and from all religions, ethnic backgrounds, and socioeconomic levels. About the only things people with disabilities have in common with one another are:

1) having a body function that operates differently;
2) facing prejudice and discrimination; and
3) having a desire to be treated with the same dignity and respect afforded people without disabilites.

Unique to the disability community is that it's the only minority group that any American can join in the split second of an accident. If/when it happens to you, will you have more in common with others with disabilities or with your family, friends, and co-workers?

The Disability Rights Movement is following in the footsteps of the Civil Rights Movement of the '60s and the Women's Movement of the '70s. While people with disabilities and advocates work to end discrimination and segregation in education, employment, and our communities at large, we must all work to end the prejudicial language that creates an invisible barrier to being included in the ordinary mainstream of life.

"Disability is a natural condition of the human experience," according to the U.S. Developmental Disabilities Act and The Bill of Rights Act, 1993. Disability is not the "problem." We need to rid ourselves of the word "problem" when talking about people's needs! A person who wears glasses doesn't walk around saying, "I have a problem seeing." She would say, "I wear (need) glasses." Recognize that a "problem" is really a need.

The real problem is attitudinal barriers. There have always been people with disabilities in our world and there always will be.

- If educators - and our society at large - perceived children with disabilities as individuals who have the potential to learn, who need the same educa-

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We must use People first Language

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While people with disabilities and advocates work to end discrimination and segregation in education, employment, and our communities at large, we must all work to end the prejudicial language that creates an invisible barrier to being included in the ordinary mainstream of life.

tion as their brothers and sisters, and who have a future in the adult world of work, we wouldn't have to fight for inclusive education.

- If employers - and our society at large - believed adults with disabilities have valuable job skills (because they received a quality education), we wouldn't have to fight for real jobs for real pay in the real community.

- If business owners - and our society at large - viewed people with disabilities as consumers with money to spend (because they're wage earners), we wouldn't have to fight for accessible entrances and other accommodations.

Many people who do not now have a disability will have one in the future. Others will have a family member or friend who acquires a disability. If you acquire a disability in your lifetime, how will you want to be described? How will you want to be treated? Disability issues are issues that affect all Americans.

Using People first Language is a crucial issue. If people with disabilities are to be included in all aspects of our communities - in the very ordinary, very wonderful, very typical activities most people take for granted - then they must talk about themselves in the very ordinary, very wonderful, very typical language other people use about themselves.

Children with disabilities are children, first. The only labels they need are their names. Parents must not talk about their children in the clinical terms used by medical practitioners. A disability label is simply a medical diagnosis.

Since the parent of a child who wears glasses (medical diagnosis: myopia) doesn't say, "My daughter is myopic.", why does the parent of a child who has a medical diagnosis of mental retardation say, "My daughter is retarded."?

Adults with disabilities are adults first. They must not talk about themselves the way service providers talk about them.

Since an adult with a medical diagnosis of cancer doesn't say, "I'm cancerous", why does an adult with a medical diagnosis of cerebral palsy say, "I'm disabled."?

In our society, "handicapped" & "disabled" are all-encompassing terms that are misused:

- People with hearing or vision disabilities don't need "handicapped" or "disabled" parking or restrooms. People with physical disabilities do need accessible parking and restrooms.

- If a "handicapped" or "disabled" entrance has a ramp for people who use wheelchairs, does the doorway have Braille signage for people with visual disabilities?

- Accommodations that enable people with disabilities to access a facility regardless of their disabilities are accessible.

- "Disabled" is not acceptable, either. Our society "corrupts" the meaning of certain words. When the traffic report mentions a traffic jam, you'll often hear, "There's a disabled vehicle on the highway." "Disabled" in that context means "broken down." People with disabilities are not broken.

- If a new toaster doesn't work, we return it, say "It's defective," and get a new one. Do we do that with babies who are born with disabilities? The accurate term is "congenital disability."

When we understand the meanings of words and how they're misused, we realize they are the tip of the iceberg of inappropriate and unacceptable language. When people with disabilities are referred to by their medical diagnoses, we have devalued them as human beings. When we devalue others, we devalue ourselves.

When we start calling things by their right names, when we recognize that people with disabilities are people first, we can begin to see how people with disabilities are more like people without disabilities than they are different. When we understand that disability labels are simply medical diagnoses, we can put them in their proper perspective.

My son, Benjamin, is 11 years old. He loves the Lone Ranger, ice cream, and playing on the computer. He has blonde hair, blue eyes, and cerebral palsy. His disability is only one small piece of his life. For many people with disabilities, their medical diagnoses define who they are.

When I introduce myself to people I don't tell them I'll never be a prima

When we start calling things by their right names, when we recognize that people with disabilities are people first, we can begin to see how people with disabilities are more like people without disabilities than they are different.

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We must use People first Language

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ballerina. Like others, I focus on my strengths, the things I do well, not on what I can't do.

I don't say, "My son can't write with a pencil." I say, "My son uses a computer to do his school work." I don't say, "My son can't walk." I say, "My son uses a walker and a wheelchair." And Benjamin isn't "wheelchair-bound." He's free when he uses it - free to go when and where he wants to go.

We know that a person's self-image is strongly tied to the words used to describe that person. We've been told that descriptions can become a self-fulfilling prophecy. If a child is told she is stupid or slow or lazy, she will probably become that. If told she's brilliant, she'll probably become that.

People with disabilities, having been described by their medical diagnoses all their lives, often must convince themselves that they are capable and have potential for success. Parents must convince themselves and their children that their kids are capable and have potential for success. If you don't believe in yourself, it's hard for others to believe in you.

We have the power to change all this for current and future generations. People first Language can change how people with disabilities feel about themselves. People first Language can change how society views and treats people with disabilities.

Benjamin goes ballistic when he hears "handicapped." I hope when he's grown, labels will be extinct.

Reprinted with permission of the author. Kathie Snow may be contacted at 250 Sunnywood Lane, Woodland Park, CO 80863-9434; Voice 719-687-8194; Fax 687-8114; e-mail: KSSnow@aol.com (Rev. 1/98)

EXAMPLES OF PEOPLE first LANGUAGE

Labels Not to Use	**People first Language**
the handicapped or disabled	people with disabilities
the mentally retarded	people with mental retardation
he's retarded	he has a cognitive disability
my son is autistic	my son has autism
she's a Downs kid, a mongoloid	she has Down syndrome
he's learning disabled	he has a learning disability
I'm a paraplegic	I have paraplegia
she's crippled	she has a physical disability
he's a dwarf (or midget)	he's of short stature or he's short
she's emotionally disturbed	she has an emotional disability
he's wheelchair bound or confined to a wheelchair	he uses a wheelchair
normal and/or healthy kids	typical kids or kids without disabilities
he's in special ed	he receives special ed services or additional support services
handicapped parking, bathrooms, etc.	accessible parking, bathrooms, etc
she has a problem with	she has a need for

Keep thinking.

There are lots more examples out there.

And practice, practice, practice.

Old habits die hard!

The Herb Lovett Memorial Fund
announces

The First Annual Rabbit Award

> *"In the earlier part of this century we believed that the new Behavioral Sciences, with a cunning scheme of rewards and punishments would remove difficult behaviors effortlessly. I think that dream is dead. I hope so. I hope that we've come to a point in our history where we have started to recognize that: the end point of pure thought is probably death; that we are not going to think our way out of these problems; and that we require a new respect for the irrational, the intuitive, and the felt. We are discovering that we need people who step out of the mode of what we created in the earlier parts of this century, to remind us of who we are and who we need to be for one another."*
>
> *Herbert Lovett*
> *Bolton Institute, 1995*

Herb had a strong tie to rabbits in his life. The rabbit is known for its ability to procreate, its fleetness, its ability to make great leaps, and its ability to call down fears and face them.

On March 20, 1999 the Herbert Lovett Memorial Fund, Inc. will be presenting its first **Rabbit,** a cash prize, to a person who has made the leap. This award is open to all. We are also looking for donations to make this a substantial fund. For more information on the Herbert Lovett Memorial Fund, write to either address below:

Apply by letter to:
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c/o Michael Dowling
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South Boston, MA 02127
Tel. 617-269-8382
Fax 617-268-8908

Send donations to:
Herbert Lovett Memorial Fund
c/o Barbara Cutler
71 Theresa Circle
Arlington, MA 02474
Tel. 781-648-1813
Fax 781-648-1813

INTERNET RESOURCES

Concerning People With Developmental Disabilities

BY RACHAEL ZUBAL AND STEVE DRAKE

The Center on Human Policy periodically produces resource reviews on a variety of topics; this article highlights some of many types of information that can be found on the Internet concerning people with developmental and other disabilities. Since there is a rapidly expanding amount of information related to disabilities available on the Internet, this is a selective, rather than exhaustive, compilation of resources that we have found to be useful and informative. We include resources and information available on: (1) electronic mailing lists and listservs; (2) newsgroups; and (3) world wide web pages.

ELECTRONIC MAILING LISTS AND LISTSERVS

Electronic mailing lists and listservs are discussion and information-sharing groups that concentrate on a specific topic area. To participate in a particular list, you send a message with a request to a specific e-mail address (see examples below) and you will then be "subscribed" to the list. Becoming subscribed to a list means that you can send a message to one e-mail address and reach all the other individuals who are subscribed to that list. You also receive any other mail sent to that address. Most electronic mailing lists send a confirmation of your subscription request, and details on the policy and philosophy of the list as well as instructions on how to contribute.

Justice for All - Justice For All and the JFA E-Mail Network were formed to defend and advance disability rights and programs at the federal level. JFA works with national and state organizations of people with disabilities to get the word from Washington D.C. out to individuals in the grassroots of disability rights. This e-mail network is moderated, which means that only those messages that are considered to be the most important are distributed. An important source of current information.

To subscribe to Justice for All, send an e-mail message to: majordomo@mailbot.com with the following in the body of your e-mail message: subscribe justice

Advocacy - This is a broad-based listserv whose subscribers include people with disabilities, parents, service providers, and other individuals concerned with advocacy efforts related to disability. The traffic on the list is light to moderate. This is recommended for anyone interested in ongoing discussion of advocacy issues.

To subscribe to Advocacy, send an e-mail message to: listserv@sjuvm.stjohns.edu with the following in the body of the message: subscribe advocacy <yournamehere>

Speak-Up - This mailing list is coordinated by Northamptonshire People First in the United Kingdom and is a private list for self-advocates to talk with each other.

Usupport - This is a second mailing list coordinated by Northamptonshire People First where both self-advocates and people who support self-advocates can talk with each other.

To join either mailing list, go to the Northamptonshire People First web page at: http://www.peoplefirst.org.uk/mail.html This portion of their web page has a form you can fill out on-line to be added to these lists.

The Beacon for [dis]Ability - This is an on-line newsletter providing highlights about the World Association of Persons with Disabilities (WAPD), a non-profit, non-political association, and its programs and disability issues.

To subscribe, send a message to: TheHub@wapd.org with the following in the body of the message: subscribe news

Our-Kids - This list is a "family" of parents, caregivers and others who are working with children with physical and /or mental disabilities and delays.

To subscribe, send a message to: LISTSERV@MAELSTROM.STJOHNS.EDU with the following in the body of the message: SUBSCRIBE OUR-KIDS <YOURFIRSTNAME><YOURLASTNAME>

DISABLED - This group aims to examine ways of exploring disability within a social and relational context. This forum aims specifically to focus on the unconscious experiences of disability, as it is socially constituted. This means examining the emotional experience of disability, from the perspective of both sides of the 'disability'/'ability' binary.

To subscribe, send a message to: LISTSERV@MAELSTROM.STJOHNS.EDU with the following in the body of the message: SUBSCRIBE DISABLED <YOURFIRSTNAME><YOURLASTNAME>

APRAXIA-KIDS - This list is a place where parents who have children with apraxia of speech (also called verbal dyspraxia, developmental apraxia of speech, etc.) can share and learn information and offer ideas and encouragement as they help their children communicate, reach their potential and thrive at home, school, and community life. Additionally, professionals are encouraged to join the list in order to understand the experience of families, learn themselves, and offer helpful comments and understanding from their perspective.

To subscribe, send a message to: LISTSERV@LISTSERV.SYR.EDU with the following in the body of the message: SUBSCRIBE APRAXIA-KIDS

NEWSGROUPS

Newsgroups are similar to electronic mailing lists in that they are discussion-based forums on specific topic areas. However, newsgroups are accessed through your Internet service provider (ISP) in a way that allows you to send and read messages without having to use e-mail. This has a great advantage in that your e-mail inbox is not overflowing

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INTERNET RESOURCES

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with messages. Connection software and procedures vary depending on your ISP. Some newsgroups that we have found to be useful and informative are:

bit.listserv.down-syn - Contributors on this newsgroup are primarily parents of children and adults with Down syndrome. Discussions and information are highly varied and include research, education, and adult living as just some of the topics that are covered.

misc.handicap - This is a very broad-based and varied newsgroup that is literally open to any topic relating to disability. Some of the information can be interesting and valuable.

bit.listserv.ada-law - This newsgroup is a resource for specific applications of the ADA. Many contributors on the list are lawyers involved in litigation regarding ADA violations.

bit.listserv.autism - Parents and professionals are the major contributors to this listserv. Contributors express the full range of opinions on controversial issues affecting people with autism (e.g., inclusion, applied behavioral analysis, facilitated communication).

alt.education.disabled - This is an active newsgroup, often involving heated debates. The most hotly and consistently debated topic is inclusive education. The majority of contributors are educators and parents.

WORLD WIDE WEB PAGES

World Wide Web pages (more commonly called web pages) are multimedia sources of information on the Internet. Below are several disability-related sites that may be of interest. These sites emphasize self-advocacy, inclusion, and civil rights.

Ability Network Magazine - http://www.ability.ns.ca/anet.html

A disability-oriented magazine with articles authored, for the most part, by people with disabilities.

Americans with Disabilities Act (ADA) Technical Assistance Program - http://www.adata.org/

The ADA Technical Assistance Program is a federally funded network of grantees which provides information, training, and technical assistance to businesses and agencies with duties and responsibilities under the ADA and to people with disabilities with rights under the ADA.

The Arc Home Page - http://TheArc.org/welcome.html

This is a very large and developing site. It offers an impressive assortment of articles, position papers, links, legislative alerts and more.

Association of Disability Advocates - http://www.icanect.net/fpa/

The Association of Disability Advocates exists for only one purpose: to provide information and assistance to individuals with disabilities in the exercise of their civil rights as provided by the Americans with Disabilities Act.

Autism Network International (ANI) - http://www.students.uiuc.edu/~bordner/ani.html

This is an autistic-run self-help and advocacy organization for autistic people.

Axis Disability Rights Website - http://www.island.net/~axis

This site contains some very good articles on inclusion and disability, as well as other progressive resources.

Bobby - http://www.cast.org/bobby

Created at the Center for Applied Special Technology (CAST), Bobby is a free web-based service that helps make web pages accessible to people with disabilities.

Consortium for Citizens with Disabilities (CCD) - http://www.c-c-d.org

CCD is a coalition of national disability organizations working together to advocate for national public policy that ensure the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

Disability Cool - http://ww.geocities.com/HotSprings /7319/discool.htm

This web site challenges all the preconceived notions about what it's like to live with a disability.

The Disability Rights Activist - http://www.disrights.org/

This site brings together much of the information needed to enable anyone interested in the rights of people with disabilities to work for those rights, including tools for activists, action alerts, announcements, and information on issues that affect the lives of people with disabilities, and contains links to several disability rights organizations and publications.

Disability Social History Project - http://www.disabilityhistory.org/dshp.html

People with disabilities have an exciting and rich history that should be shared with the world. The ways in which disabled people have acted and have been treated and viewed must be examined within the social, political, economic, and religious climates of the times and cultures. This project will present images and information about disabled historical figures and events in an attempt to give an introduction to disability social history.

Electric Edge: Online Edition of Ragged Edge Magazine - http://www.ragged-edge-mag.com/

This online edition of Ragged Edge magazine (the successor to Disability Rag) includes the best writing today about the most "ragged issues"—assisted suicide, long-term care, rights, access, and covers the disability experience and what it means to be a crip at the turn of the millenium.

Facilitated Communication Institute - http://soeweb.syr.edu/thefci

This site offers articles, research summaries and other material relating to facilitated communication (FC).

Family Village: A Global Community of Disability-Related Resources - http://www.familyvillage.wisc.edu/

Family Village is a global community that integrates information, resources, and communication opportunities on the

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INTERNET RESOURCES

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Internet for persons with mental retardation and other disabilities, their families, and those that provide them services and supports.

Family Voices - http://www.familyvoices.org/~vrosales/

"We are families from throughout the United States who have children with special health needs. We are also caregivers, professionals, and friends whose lives have been touched by these children and their families. We are a diverse group, representing a wide variety of children, health conditions, families, and communities. Our concern for children brought us together."

Federation for Children with Special Needs - http://www.fcsn.org/home.htm

Organized in 1975 as a coalition of parent groups representing children with a variety of disabilities, the Federation operates a Parent Center which offers a variety of services to parents, parent groups, and others who are concerned with children with special needs.

GLADNET - http://www.gladnet.org

The Global Applied Disability and Information Network on Employment and Training, better known as GLADNET, brings together research centers, universities, enterprises, government departments, and other groups for the promotion of research as well as the collection, analysis and exchange of information concerning people with disabilities and work.

GnarlyBone News - http://www.realtime.net/cyanosis/gnarly

This online newsletter supports and promotes disability activism with a focus on arts, culture and media. This site includes information on how to subscribe and access past issues and links to other disability activism resources.

Human Services Research Institute (HSRI) - http://www.hsri.org

HSRI works to develop support systems for children, adults, and families, and enhances the participation of individuals and their families to shape policy and service practices.

Inclusion Press Home Page - http://www.inclusion.com

"Inclusion Press is a small press striving to produce readable, accessible, user-friendly books and resources about full inclusion in school, work, and community."

International Coalition on Abuse & Disability - http://www.quasar.ualberta.ca/ddc/ICAD/icad.html

From the University of Alberta, a valuable resource regarding the issues surrounding abuse and disability.

Institute on Community Inclusion - http://web1.tch.harvard.edu/ici/

The Institute for Community Inclusion supports the rights of children and adults with disabilities to participate in all aspects of the community.

Institute on Community Integration - http://www.ici.coled.umn.edu/ici/

"We believe that persons with developmental disabilities should live as valued members of our communities, receiving the services and supports they need to fully develop their potential."

Institute on Disability - http://iod.unh.edu

The Institute is a University Affiliated Program (UAP) located at the University of New Hampshire that promotes full inclusion of people with disabilities in their communities.

Institute on Disability Culture - http://www.dimenet.com/disculture/

"People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives, our culture, infused from our experience of disability."

International Leadership Forum for Women with Disabilities - http://www.prodworks.com/ilf/

This is a continuing information web site. The purpose the forum is to create an international support network with an emphasis on technical assistance for women with disabilities. This web site was created to provide information beyond the 1995 international womens conference in Beijing, China and to be enhanced with new information as it becomes available over time.

Kids Together - http://www.kidstogether.org

This non-profit organization, co-founded by parents and organized by volunteers, supports the belief that children with disabilities, like all children, have the need to be welcomed, cherished and embraced in our communities. This site is designed to provide helpful information and resources to enhance the quality of life for children and adults with disabilities, and communities as a whole.

Mainstream Magazine - http://www.mainstream-mag.com

On-line version of the well-known disability magazine.

National Association of Protection and Advocacy Systems (NAPAS) - http://www.protectionandadvocacy.com/

NAPAS is a national voluntary membership organization for the federally mandated nationwide network of disability rights agencies, protection & advocacy systems (P&As), and client assistance programs (CAPs).

National Association of State Directors of Developmental Disabilities Services, Inc. - http://www.NASDDDS.org/

This non-profit organization is devoted to expanding and improving public services to individuals with mental retardation and other developmental disabilities.

National Council on Disability - http://www.ncd.gov/

The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting Americans with disabilities.

The National Organization on Disability - http://www.nod.org

The National Organization on

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INTERNET RESOURCES

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Disability promotes the full and equal participation of America's men, women and children with disabilities in all aspects of life.

The National Home of Your Own Alliance - http://alliance.unh.edu

The National Home of Your Own Alliance is a partnership between the Federal government and nationally recognized advocates and leaders whose goal is to create housing and support opportunities that people choose and control.

National Parent Network on Disabilities (NPND) - http://www.npnd.org/

NPND was established to provide a presence and national voice for parents of children, youth, and adults with special needs.

National Rehabilitation Information Center (NARIC) - http://www.cais.net/naric/

NARIC is a library and information center on disability and rehabilitation, and collects and disseminates the results of federally funded research projects.

New Mobility Magazine - http://newmobility.com

"Disability is news, art, politics, humor, healing, recreation, travel, showbiz and rehab-biz, and that's what we do."

Northamptonshire People First - http://www.peoplefirst.org.uk

A self-advocacy organization from the United Kingdom of people with disabilities speaking up for themselves. This site includes links to several other self-advocacy organizations.

Not Dead Yet - http://www.acils.com/NotDeadYet/

Not Dead Yet is a national activist organization which opposes the legalization of physician-assisted suicide and places emphasis on the value of life.

Parent Advocacy Coalition for Educational Rights (PACER) Center - http://www.pacer.org/

PACER's mission is to improve and expand opportunities that enhance the quality of life for children and young adults with all disabilities—physical, mental, emotional, learning—and their families.

The Oaks Group - http://www.jps.net/wcoffelt/oaks.html

The Oaks Group is a value based stakeholder organization whose members believe persons with developmental disabilities should be fully included in the mainstream of community life, that children should have the opportunity to grow up in families, and adults should receive the help needed to live as close as possible to the way people without developmental disabilities live.

On A Roll - http://www.onarollradio.com

The only commercial, syndicated radio talk program for the disability community.

Society for Disability Studies - http://www.wipd.com/sds/

The Society for Disability Studies (SDS) is a nonprofit scientific and educational organization composed of social scientists, scholars in the humanities, disability rights advocates, providers, and agency personnel concerned with people with disabilities.

TASH - http://www.tash.org

Formerly The Association for Persons with Severe Handicaps, TASH is an international advocacy association of people with disabilities, their family members, other advocates, and professionals working toward a society in which inclusion of all people in all aspects of community is the norm.

Through the Looking Glass (TLG) - http://www.lookingglass.org

This is a community, non-profit organization which emerged from the disability independent living movement and whose mission has been to create, demonstrate and encourage resources and model early intervention services which are non-pathological and empowering. TLG has pioneered clinical and supportive services, training and research serving families in which one or more members—whether parent or child—has a disability or medical issue.

Training Resource Network (TRN) - http://www.oldcity.com/trn/

Publisher that offers resources on the full inclusion of people with disabilities in their communities, especially on the topics of supported employment, person-centered planning, supported living, and self-determination.

Uppity DisAbility Internet Resources - http://gandalf.umcs.maine.edu/~asl/upmain.html

"Socially progressive site for like minded disAbled people."

World Institute on Disability (WID) - http://www.igc.apc.org/wid/

WID is an international public policy center dedicated to carrying out cutting-edge research on disability issues and overcoming obstacles to independent living.

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Escaping from the LABEL TRAP

BY MICHAEL W. SMULL

While we talk about supporting people, our practice is to place people. We group people who have the same labels into the same homes. We determine who is "ready" for work or a smaller living setting based on performance assessments that have little to do with the real requirements for a job or another place to live. Often, pay lip service to preferences and desires but do nothing to meet the modest requests that people are making. As was noted in a 1990 publication on independent living:

"(People with developmental disabilities) are no less independent than young urban professionals who are too busy to do for themselves... We do not hear reports of executives who are unwilling (or unable) to prepare their own meals being forced back into their parental homes, or to live in congregate arrangements." (Lozano, 1990)

To illustrate the absurd nature of the decisions we make in our program model let us see what would happen if we applied it to college students. If the disability system ran the university the first thing that we would change would be how people are housed. Freshman would be assigned roommates, floors, and dorms based on SAT scores. We would have separate dorms for each of these groups:

SAT Score	**Classification**
1600 - 1451	**Profoundly Clever**
1450 - 1301	**Severely Clever**
1300 - 1151	**Moderately Clever**
1115 - 1001	**Mildly Clever**
1000 - 850	**Borderline Clever**

While each dorm would be required to be restricted to one group, e.g. the severely clever, within the dorms roommates would be within 15 SAT points of each other. We would debate whether those in the "borderline clever" group are really college material, but we could call them athletes.

We need to start with the individual rather than the program and to listen to what the individual is asking for rather than simply looking at what exists. For the disability system the challenge is to learn what must be present or absent in each setting for each individual. We need procedures that help to lift us out of our habitual patterns of thinking and provide us with an alternative structure.

Having solved the problem of selecting dorms and roommates we would turn our attention to the next issue, that of choosing major areas of study. We know that freshman really do not know what they should study. Instead of the inefficient process of having freshman pick majors and change majors, we would simply review the SAT results and select the area where they demonstrated the poorest performance. We know that what is important is remediating deficits. This will also make course registration more predictable as many seniors will still be failing the same courses that they began taking as freshman.

The next issue where we can be of assistance to college administrators is in the area of behavior. Freshmen are notorious for the frequency and severity with which they exhibit maladaptive behaviors. It seems that all of the behaviors that parents had suppressed for 18 years emerge during the freshman year. Colleges have attempted to tolerate all but the most outrageous of these behaviors. As the disability experts running the University, we can do better. Freshman will have to earn points in activities of "daily university living" (in areas such as personal hygiene and dorm room maintenance) in order to have privileges such as having pizza delivered to their rooms. Where we face more challenging behaviors, we can make attendance at football and basketball games a contingent reinforcer. We can introduce the idea of the IDP (Individual Dorm Plan) and revolutionize the management of the behavior of college students.

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LABEL TRAP

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Where students have roommates that they do not like (despite our scientific method of matching) we have the answer. The old method of simply allowing students to select and change roommates at will is appallingly inefficient. We know that there is no real necessity to change roommates. With our technology we can introduce behavior programs and structured interactions. We will not need to allow students to change roommates simply because they want to. We will not listen to the students who say that this means that they have to spend more time with people that they hate.

If we were to actually attempt such a system in a college setting it would only be a matter of days or weeks before the students rose up in revolt. People with disabilities have been more tolerant. They have largely accepted our practices. Where individuals have objected they have been the subjects of powerful interventions for "maladaptive behavior." To keep the promise of supported living and to redeem the promise of supported employment we need to not only change our practice but to change the way we think.

Having agreed that we need to look beyond labels, we need help in escaping from our label trap. We have conditioned ourselves into a pattern of thought which links labels with programs. We need assistance in developing new patterns which assist us in recognizing the characteristics of individuals which determine the settings in which they would choose to live, work, and play. We need to start with the individual rather than the program and to listen to what the individual is asking for rather than simply looking at what exists. For the disability system the challenge is to learn what must be present or absent in each setting for each individual. We need procedures that help to lift us out of our habitual patterns of thinking and provide us with an alternative structure.

We must avoid perverting the provision of support services. We have been so seduced by labels that we re-label programs with support names and believe that we have achieved our goal. When people are simply assigned supported employment jobs (without choice), when supported living only means that we put the lease in the name of someone with a disability who has not chosen where to live or who to live with, we have not changed the way we think about people with disabilities. We must redeem our promises.

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This article first appeared in an issue of AAMR News & Notes. Michael Smull may be reached at Support Development Associates, 301-564-9572;
e-mail <mwsmull@compuserve.com>

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Changing the News about Disability:

Why we need to and how to do it

BY MARY JOHNSON

As I sat down to read our Sunday paper recently, my eye caught the headline across the top of the Metro section: "Racial slur painted on city building." I read on. The word "nigger" had been spray painted on a government building in one of our community's small, incorporated cities and the word had remained there a month. An official said the work order for removing it had "slipped through the cracks."

The mayor of the city of Hillview told the reporter he hadn't been aware of the vandalism "until a civil-rights activist, the Reverend Louis Coleman, complained about it yesterday." The story went on to report that the graffiti had been promptly removed after Reverend Coleman had complained.

Knowing what I did of Reverend Coleman, I knew he'd also called the local media to tell them about the story. What was the result of these efforts? The story led the top of the Metro section of our Sunday newspaper, a newspaper with a circulation in the millions.

Glancing over the Metro section, my eye fell on another article: "Seriously, laughter is beneficial, doctor says," read this headline. The story reported on a speech to a local group given by Dr. Clifford C. Kuhn, a professor of psychiatry at the University of Louisville's medical school. Skimming the story, I read these lines: "He said political correctness has been taken too far, citing the example of a Halloween costume that included a pirate's mask with a patch over one eye that was called offensive to blind people. The costume would not be offensive to the blind 'if you don't tell them,' a laughing Kuhn said."

> *Controversy increases the chances of your issue getting covered. A protest, a demonstration, a lawsuit, charges of bias made by your group against an institution (such as the entertainment industry) are always more interesting to reporters than "positive" stories. It's just a fact of life. However, controversy must have substance.*

A few hours later, I found I was still fuming. The incident about the racial epithet had been taken seriously — by the Reverend Coleman and by the newspaper. Racial issues — thanks in part to Reverend Coleman's activism — were taken seriously by our local media. But the story about the pirate's costume reminded me how far we still had to go.

The pirate's costume story was being used by this respected professor of psychiatry to show how people are often "too sensitive", too "politically correct." It seemed that whenever someone wanted an example of "political correctness" run amok, the example that was used related to disability.

This had been going on since the early 1990s. Writers who wouldn't dare ridicule racism, sexism, anti-Sexism or "homophobia" lampooned political correctness by ridiculing disability terms. "What editor could resist the tale of academic orthodoxy in which cracked rules of civility require short people to be referred to as the vertically challenged?" wrote Anthony DePalma in the September 25, 1991 *New York Times*. *Chicago Tribune* columnist Joan Beck chose "ableism" for her prime example of what's ridiculous about political correctness. She called it "a spoof of itself."

"People who are politically correct are pushing 'differently-abled,' " Sol Steinmetz, Executive Editor of the Random House Webster's College Dictionary told the *New York Times*'s Richard Bernstein. "'Differently-abled,' " wrote Newsweek's Jerry Adler, "is a 'term created to underline the concept that differently-abled individuals are just that, not less or inferior in any way.' Well, many people with handicaps surely do develop different abilities, but that is not what makes them a category. They lack something other people possess. It does violence to logic and to language to pretend otherwise. If people could choose, how many would be 'differently-abled?' "

Using racial epithets was wrong, everyone knew that. But disability issues are still not seen by the media as serious issues in the same way as racial issues, or issues of discrimination against women or gays.

Before the 1980s, there was only sporadic coverage of the disability movement and its issues. The media wrote about "courageous cripples" who overcame their disabilities, much the same way that an earlier generation of reporters had written about Negroes who were "credits to their race." Or they wrote about tragic cases of "poor cripples" who needed help to get a wheelchair or a brace; stories that were smaller versions of the telethons.

During the 1980s, as people with disabilities began to push seriously for

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Changing the News about Disability

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> *The view that the desires of people with disabilities for access is silly at best, and selfish and wrongheaded at worst, has been the consistent viewpoint in the press...and is growing stronger. It is against this backdrop of hostility surrounding disability issues in the national media (that often trickles down to local news outlets) that we must look to our own efforts to gain media attention.*

civil rights and as some of the effects of the Rehabilitation Act and the Education for All Handicapped Children Act provisions began to take root, a new tone crept into reports about people with disabilities. Andy Rooney, complaining about violinist Itzhak Perlman's campaign to make Carnegie Hall accessible, wrote "No one is against the handicapped ... but we cannot make life normal for people who have bodies that do not work properly."

The *New York Times* opposed making subways accessible to people that use wheelchairs using very similar language. "The first object of a wise but concerned policy cannot be to make people with serious disabilities move as if they did not have them," read its Jan. 3, 1984 editorial. The *Times* was echoing an editorial in the July 1, 1982 *Washington Post*, in which it complained that "deaf Amy Rowley" had no right to an interpreter in a regular classroom. "There are limits to what society can afford, limits which suggest that the goal of some handicapped rights groups — that people with handicaps be able to function as if they did not have them — is simply not attainable."

The views expressed by Rooney, *The New York Times* and the *Washington Post* were echoed again in the early 1990s in an all-out attack by right-wing Manhattan attorney Philip Howard, whose 1993 best-seller, The Death of Common Sense, wrote that "the handicapped" were ruining America with their incessant demands. The view that the desires of people with disabilities for access is silly at best, and selfish and wrongheaded at worst, has been the consistent viewpoint in the press since then — and is growing stronger.

It is against this backdrop of hostility surrounding disability issues in the national media (that often trickles down to local news outlets) that we must look at our own efforts to gain media attention.

Stories which focus only on individuals, but which do not further the agenda for more accessible housing, compliance with the Americans with Disabilities Act, attendant services, and so on, persist because most journalists don't know that there are important disability issues that they should be covering. If asked why they don't cover disability rights issues, reporters and editors may say that such issues affect only a small minority, that they don't have an impact on their broader audience. We know they're wrong. But what they're really saying is that, to them, these experiences seem like individual problems; they're not issues that affect the whole of society.

Rather than trying to generate our own stories that do not seem "newsworthy" to editors, a way to change the public debate around disability issues is to do what Reverend Louis Coleman and his civil rights group do: they focus on broad-based issues in the news, pointing out the racism. When the University of Louisville planned a new football stadium, Coleman raised to the media the issue of minority contracts in the construction. This is how Coleman has gained credibility in the local media. When Coleman calls news reporters now, they listen. That's because he's been persistent.

If your group filed a lawsuit two weeks ago against the state for failing to comply with the Americans with Disabilities Act, it's "old news" to the media. Reporters will wonder why you waited two weeks. They won't cover the story. Timeliness is one of the most important keys to getting coverage. Reporters need to know about the lawsuit, and the "why" behind it, well before you filed it. If you picketed an inaccessible restaurant yesterday, local media won't be able to do a thing for you in terms of coverage. You must tell them in advance.

Controversy increases the chances of your issue getting covered. A protest, a demonstration, a lawsuit, charges of bias made by your group against an institution (such as the entertainment industry) are always more interesting to reporters than "positive" stories. It's just a fact of life. However, controversy must have substance. If you can't back up your charges with proof or substantial evidence on your side, then you simply lose the media's interest. For example, if you charge a film producer with bias, you need to be able to explain specifically what about the movie makes it biased (is it the casting? the story itself? the language? the way the person with the

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Changing the News about Disability

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'disability is portrayed?). If you can't substantiate your allegations, you will be branded as a group that "doesn't know what it's talking about." Be controversial, but do your homework!

Whenever we begin planning to get coverage of some event or issue, we must ask ourselves: will the coverage we are seeking help "frame the debate" on current issues that affect our lives? Will this coverage further our agenda on issues like attendant services or enforcement of the ADA?

There is nothing better than finding a disability rights angle to a big, breaking news story — on any issue — to propel disability issues into the news in a way that makes disability rights seem important to society. Calling the reporter responsible for the "hot" news story, and presenting a disability rights "spin" on the issue is a good way to inject a disability rights issue into the news in a way that makes it seem important to a broad range of people. Doing this also gives you a chance to "frame the debate" from a disability rights perspective.

Reporters don't have time to digest a lot of material. The news business runs on tight deadlines; things have to be processed fast. If an angle is complicated or requires a lot of digging, a reporter may simply ignore it. Even if it meets other criteria of newsworthiness (for example, if it's really controversial), a reporter won't give your angle much attention if it isn't presented clearly and simply. That's your job.

Take a hint from *USA Today*. Most of their stories are very short and to the point. Pick up a copy of the newspaper for a week or so. Study what's in each story. Notice in particular how the story starts - that is, how the lead paragraph is written. Write your angle as if it were a *USA Today* story. Make it fit on one page. Get the most important information in at the top. Hook the reporter in the first sentence.

Work on this technique with others in your organization until you are all comfortable with figuring out how to find the newsworthy angle and hooking a reporter or assignment editor with it. You can learn what angles can "hook" the reporter you're targeting by reading how the newspaper covers stories. Watch TV news broadcasts and listen to local radio news shows. As you follow the daily news, get into the habit of analyzing stories about organizations or issues which you think do get good press coverage. Ask what angle is being covered in this story. Why is this angle considered newsworthy? What isn't being covered? Why not? Can I figure out why a reporter chose to cover one angle of a story to the exclusion of others?

> *Whenever we begin planning to get coverage of some event or issue, we must ask ourselves: will the coverage we are seeking help "frame the debate" on current issues that affect our lives? Will this coverage further our agenda on issues like attendant services or enforcement of the ADA?*

Take notes on index cards. Record which reporters cover which issues regularly. Note what "angles" they use frequently. Study your notes before you contact the reporter, so that you know their approach and can "speak their language." If they aren't interested, don't get discouraged. Part of what you're doing is establishing a relationship, letting reporters know your group is out there with story ideas.

Remember to keep the issue simple. Focus on things like access denied, civil rights, the moral rightness of integration. These are common themes most people understand today. Disability rights is a very simple and moral concept. Don't make it complicated or academic. Think about explaining your issue to the average person on the street. And think about issues that can "re-frame the debate" AWAY from the viewpoint that people with disabilities are simply malcontents who "want too much." You can show how an inclusive society benefits us all.

None of this strategizing will help, however, if your issue isn't clear and focused, and if you don't have your facts easily accessible for reporters. By disciplining yourself, doing your homework and providing clear, explanatory materials, you can make it easy and simple for reporters, editors and producers to understand why a story is newsworthy, and what the angle is.

Do this enough and you'll begin to instinctively learn what kinds of things reporters and their editors consider newsworthy. When you want to get media coverage, push similar angles. If the reporter becomes interested, you will need to have many more facts at hand, and be prepared to give the reporter all the information he/she needs. You will need to have other sources to refer to the reporter. You will need to have lined up individuals affected by the issue who can talk to the reporter about how the issue has played out in their lives, and point to disability rights movement sources who can discuss the issue. Remember: you can re-frame the debate — if you plan, if you devote time to it, and if you use your resources well.

Mary Johnson is Editor of Ragged Edge magazine, and co-author of the book Making News: How to get news coverage for disability rights issues, available for $10.95 from The Advocado Press, P.O. Box 145, Louisville, KY 40201. To contact Ragged Edge magazine, write P.O. Box 145, Louisville, KY 40201, or visit Ragged Edge's website at http://www.ragged-edge-mag.com

A Self-Advocate Speaks Out Against Aversives

BY MICHAEL J. KENNEDY, WITH DOUG BIKLEN

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When I was in Rome (a New York State institution that is now closed), I saw a lot of people who I had lived with given drugs to keep them passive. If that didn't work, the staff would use restraints. Using a straightjacket, they tie you up and put you in a room that is padded. There was nothing there but a little window. You couldn't see out, but they could see in. They would leave you in there for three, four hours, sometimes for two days. There was no furniture and no toilet. Usually people would end up going to the bathroom on themselves because they couldn't get nobody's attention to take them to the toilet.

Another punishment was "the table." It was like an examining table, but they would strap you down on it and they'd leave you on the table in a room for hours. The room was white and had florescent lights in it. Every once in a while they would look in the window or unlock the door and look in. Why they would lock the door I'll never know, because you can't get out once you are strapped down. Then after a while they would come and take you out and they would say, "Well, have you had enough?" or "Are you going to behave now?" Or they'd make a snide comment like, "Well if you do this again, you're going to be right back here."

And it's like you could see what the person (who had been punished with these restraints) was feeling and they wanted to say: "if you had listened to me about what's going on I wouldn't be acting out in the first place." You could see it on their facial expressions. At least I can.

The staff made me watch some of this stuff (the abuses, the use of restraints) because they figure if I watch it, I'll shut up and won't say anything. But what it did to me, it made me speak out stronger on behalf of other people with disabilities because somebody had to take that step and go forth, even though I knew that I was putting my life on the line. Somebody had to speak up. When staff are drugging people and tying them up it's because the institution allows it.

One staff person punished me for turning him in. He pulled my right hip right out of the socket. I live with that pain all my life. In order to get it fixed, they'd have to put in a plastic hip and they don't know if that would work. Any anyway, I can't afford to be out of work. I'd be out at least six months to a year. That was the result of me turning somebody in for physically abusing people.

At Rome I watched people, the residents, when they are not upset and trying to get their point across about a certain issue going on in their life and nobody is listening. As soon as they get upset, then you've got everybody coming from all over. You've got security coming, you've got the nurse coming, you've got somebody coming with a straightjacket. It's like a domino affect. If one person sees another person getting upset, then they get upset, too, because they are concerned about why nobody is trying to find out why [the first person] was upset.

I'll give you one example. I lived on this one unit with this fellow in Rome and one day he got up and he wasn't feeling well. He tried to tell the staff that and they said, "well, you've gotta go to your day program, just go." And he didn't want to go because he didn't feel well. He got so upset because he didn't feel well. He needed medication for an upset stomach or whatever it was. They wouldn't listen to him, so he got so mad that he ended up hitting one of the staff. Because he hit one of the staff, they locked him up.

I said to the nurse who came that if you take him down to the doctor's office, he could probably write on a piece of paper that he doesn't feel well. So they took him down there and the doctor examined him and he had an upset stomach because he had the flu. But the only way that he could get somebody's attention was to act out like that. It's a shame that you've got to act out just to tell somebody that you are not feeling well.

The mentality of the staff was: "They're (the residents) disabled, they're retarded, so they don't know how they feel." That was the mentality.

Even though today it's gotten better, still there seems to be the mentality where some people who work with people with disabilities just see them as that disability and nothing more. And they focus on what we can't do rather than what we can do. They don't stop to think that it could be their son or daughter.

One of the biggest things is that they don't look at us as individuals who have feelings, wants, and desires like everybody else. These doctors, nurses, and other staff don't take the time to get to know you because in the institutional setting, and even in the group home, there is so much turnover. So how do they get to know you? The institution was always shifting staff from unit to unit to

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SPEAKING OUT AGAINST AVERSIVES

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> **One of my advocacy dreams is to do away with aversives. If I had one dream it would be that people can get the help they need without getting hurt.**

unit, so they couldn't get to know what a person's likes and dislikes are, what makes them feel good, what makes them sick.

For those who still believe in aversives, I have to ask, do you really care about people, are you a human being? Because if you don't want to try any other way to learn to communicate, to hear people's desires and fears and so on, if all you can do is use aversives, I have to ask are you a human being? My answer — in my own mind — is no. If you were a human being, you'd ask and try to explore the best way that individuals understand. I will say that in some ways it's gotten better, but I won't say they don't still do it.

One of my advocacy dreams is to do away with aversives. If I had one dream it would be that people can get the help they need without getting hurt.

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UNLEASH THE POWER

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Baltimore Sun. Although we needed to tell our caregiving problems to get our point across, my favorite article was the positive one in the *Sun* - with the picture of the Governor smiling and shaking my daughter's hand.

After the press conference our strategy focused on legislators on the money committees who needed to approve the DDA budget before it went to the full legislature. During February, we solicited champions and asked them for help and suggestions. For those we were unsure of, we descended on their offices with constituent families. Additionally, since we knew that decisions would be made by the beginning of March, we planned our Day at the Legislature for late February. The Governor spoke, and a couple of hundred people fanned out to visit their legislators and reinforce our message. We also crowded the room of the Senate budget committee hearing, where we set up our "FACES" display as we had at the House hearing a week before. At the same time, we kept those letters coming.

The upshot of the saga is that the DDA budget sailed through the budget committees and, in early April, the full legislature approved it without a hitch. We have our Initiative, set out as a five-year plan. But we mustn't forget that funds have officially been approved for only one year. We can't sit back, especially with elections coming. We need to keep the grassroots activated and continue our behind-the-scenes negotiating to make sure everything doesn't come crashing to a halt in 1999. Moreover, we'll have to look beyond the five years to ensure that, because of foresight and planning, we preclude another backlog.

But while we remain vigilant, we are moving forward with the challenge of implementation. By February, before the Initiative passed, DDA began planning. The Director hired Kathy Perkins to oversee the implementation process. She is working with an Advisory Committee made up of advocates, a service coordinator, a self-advocate, and providers.

Representatives of The Arc are part of that team. We have had exhaustive 3-hour-long weekly meetings to set priorities and parameters for how the money is spent. DDA directors and other professionals make up the implementation team, which also gives input. Final decisions are made by Diane Coughlin.

■ ■ ■

> **With professionals, self-advocates, and families as partners, we've come this far beyond where we ever dreamed. Who can stop us now?!**

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Throughout May, DDA officials invited all Waiting List families to regional meetings to explain the Initiative, its guiding principles, what had been decided, and what would happen next. By the end of August, service coordinators will have met with everyone on the Waiting List to begin the person-centered planning process. What a daunting task!

For me, what this has always been about is the families, all the wonderful people I met throughout the year. We told them that if they unleashed what I call "people power," they couldn't lose. But underneath I was always afraid that, when it came down to the end, we might have to compromise and let them down. That didn't happen. As we promised, for residential supports everyone who has a caregiver 55 or older as of January 1, 1998, will get services within the five years.

We have a challenge ahead of us to serve so many people in such a short time and adhere to our principles. Everyone working on this Initiative is committed to using this wonderful opportunity to not only serve as many people as possible, but to serve them well - and in new and exciting ways. With professionals, self-advocates, and families as partners, we've come this far, beyond where we ever dreamed. Who can stop us now?!

Joyce Lipman is President of The Arc of Maryland and Waiting List Campaign Chair. The Campaign Coordinator, Sue Dotson, is the wife of TASH's Information Systems Specialist, Dan Dotson. For more information on Maryland's Waiting List Campaign, contact Waiting List Watch c/o The Arc of Maryland at 410-571-9320.

BEST COPY AVAILABLE

The Special Education Service Agency - Anchorage, Alaska

SESA currently has a vacancy for an Education Specialist in the following specialty area. For more information about our organization, visit. our website at http://www.sesa.org.

Education Specialist - Multiple/Significant Disabilities

Provide technical assistance and consultation to educational teams working with students with the following disabilities autism, moderate/significant mental retardation, orthopedic impairments, other health impairments, traumatic brain injury, and/or multiple disabilities in rural/remote Alaskan school districts.

Minimum Qualifications

(1) Master's degree in education with an emphasis on one or more of the disabilities listed above;
(2) Minimum of three years recent experience with this population;
(3) Qualify for Alaska DOE Special Education Type A (teacher) Certification;
(4) Demonstrated knowledge and skill levels in current "best practices" in the education of students with multiple/significant disabilities;
(5) Current knowledge of assistive technology options for students;
(6) Ability to work collaboratively with team members; and,
(7) Excellent health and the ability to travel extensively and independently in rural/remote Alaska.

Preferred Experience

Direct experience with students with multiple/significant disabilities across age ranges - preschool through high school - and various ability levels; Providing training to professionals and/or paraprofessionals; and Inter-agency networking and collaboration.

Contact: John Lund, Program Administrator — Special Education Service Agency
2217 E. Tudor Road, Suite 1 • Anchorage, AK 99507
(907) 562-7372 • Fax: (907) 562-0545 • e-mail: jlund@sesa.org

INCLUSION PRESS

Upcoming Events

- *Creative Facilitator Course.* Learn creative tools for teams and for change such as:MAPS, PATH, Solution Circles, Six Thinking Hats, Graphic and Process Facilitation and more!

  — January 27-30, 1999 in Toronto (limited to 35 participants)

- *Design for Change.* Something totally new for people who really want to change their organizations. Open only to people who have been involved with MAPS and PATH and have participated in The Summer Institute, The Creative Facilitator or other events with Jack, Marsha and John.

  — February 24-27, 1999 in Toronto (limited to 20 participants)

- And don't forget *The 1999 Toronto Summer Institute on Inclusion, Community and Diversity.* A unique one week Learning Marketplace experience featuring an international faculty team. An experience in learning and living you won't soon forget.

  — July 3-9, 1999 in Toronto (limited to 125 participants)

For information on any or all of the above events, contact: Cathy Hollands or Marsha Forest and Jack Pearpoint, Inclusion Press, 24 Thome Cres., Toronto, Ontario M6H 2S5 Canada. Telephone: 416-658-5363; Fax: 416-658-5067; E-mail: 74640.1124@compuserve.com or check out Inclusion Press's web site at http://Inclusion.com

Realize the Promise

On a radiant fall afternoon in Washington, D.C., several hundred parents, children, disability rights advocates and others gathered on the Ellipse near the Capitol to protest the lackluster — and in many instances, non-existent — enforcement of the Individuals with Disabilities Education Act (IDEA). Rally participants complained that students with disabilities continue to receive education in public schools that is of poorer quality than their counterparts without disabilities.

Sunday, October 11th was billed as "A Day to End Special Segregation," a rally and action designed to issue a directive to public policymakers that the implementation and absolute enforcement of IDEA must become a reality. The event was a collaborative effort organized by national parent and advocacy groups, including TASH and MAIN (The Mighty Alliance for Independence Now). Speakers included several internationally known disability activists such as Justin Dart, 1998 Presidential medal of Freedom recipient; TASH Board member Mike Auberger, co-founder of ADAPT; Janine Bertramkemp, activist and widow of disability rights pioneer, Evan Kemp, Jr., Sarah Jacobs, who delivered a special message from Vice President Al Gore; Jonathan Young, White House Associate Director of Disability Outreach; Wilson Buswell and Aaron Flint, national student leaders from Colorado; Elisabeth Healey, elected member and Past President of the Pittsburgh School Board and current President of the TASH Board of Directors, and many others. Greg Smith, host of the nationally syndicated radio talk show "On A Roll", served as master of ceremonies.

The rally culminated in a march from the Ellipse to the Capitol where lawmakers were still in session trying to pass a budget bill before adjourning for the year. Rally participants presented a signed petition at the Capitol demanding that policymakers implement and enforce IDEA.

Greg Smith (far left) of the nationally syndicated radio talk show, On A Roll, served as Master of Ceremonies.

Rally participants marched from the Ellipse to Capitol Hill

DARTS FOR INCLUSION

Younger rally participants got a chance to enjoy life-size cartoon characters.

TASH Board member Mike Auberger was one of the day's outstanding speakers.

End Special Segregation Now!
End Special Segregation Now!

Yoshiko (l) and Justin Dart

TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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( ) Self-Advocate
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Moving?
Please notify TASH of your new address.

General Membership (individual)	$88
Agency/business/university/college/library/school (allows 3 conference attendees at the member rate)	$200
Self Advocate, Parent, Full Time Student, Direct Careworker/Paraprofessional/Personal Attendant (for whom payment of full fee would present a hardship)	$45
Family (group rate)	$136
Lifetime Member	$1000

Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information.

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( ) Include an additional $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

Please make check payable to: TASH
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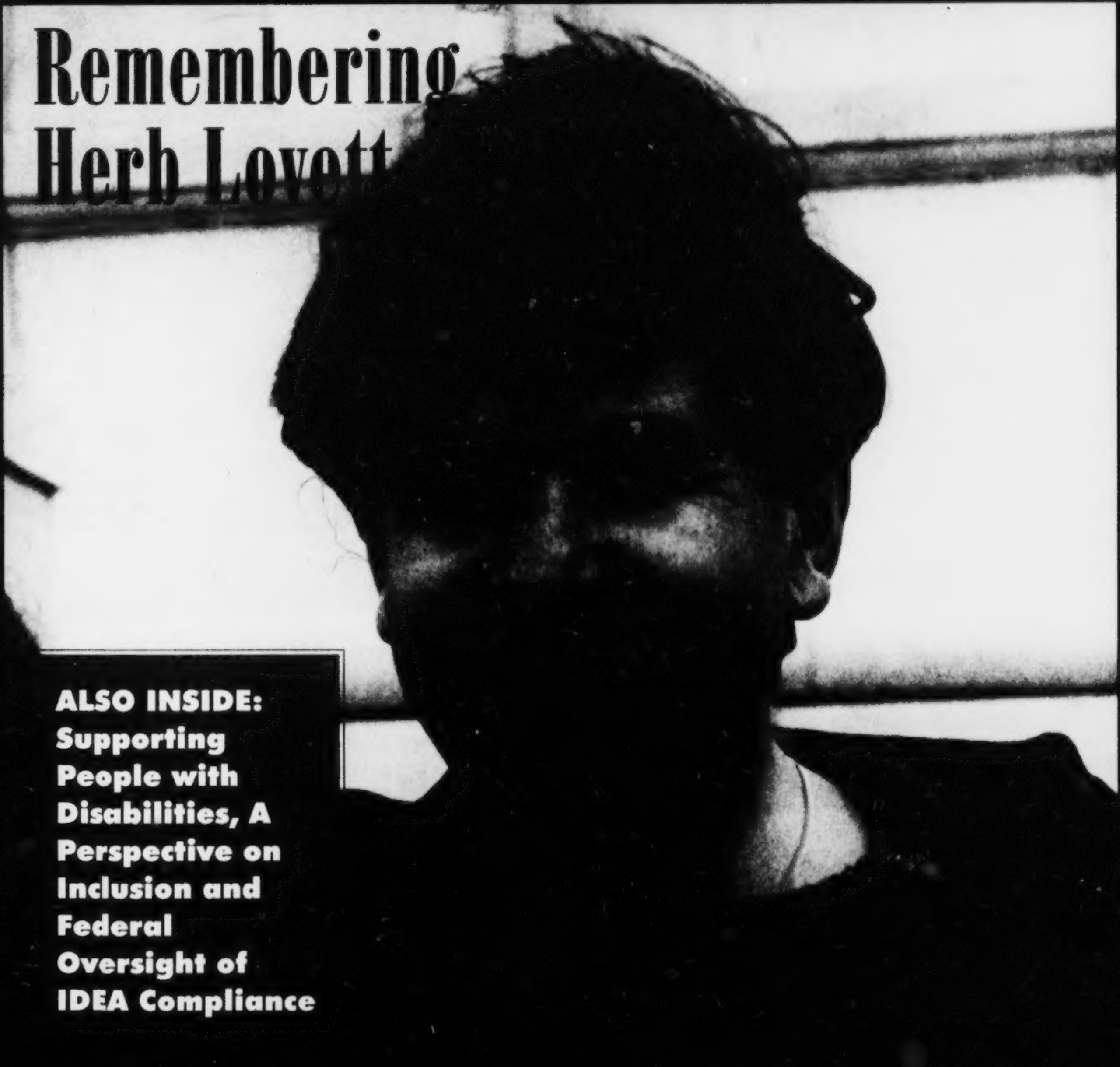
OCTOBER 1998

Newsletter



Remembering Herb Lovett

ALSO INSIDE:
Supporting People with Disabilities, A Perspective on Inclusion and Federal Oversight of IDEA Compliance

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 108 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

View from a BOARD MEMBER

BY TIM KNOSTER AND LINDA RAMMLER

It is with mixed emotions that we provide this preface to this particular *Newsletter* in memory of our friend and colleague, Herb Lovett, Ph.D. The reason for our sadness is clear as we, and countless others, continue in our efforts to come to terms with Herb's death. Ironically, at the same time we are elated about the focus of this *Newsletter* as each of us continue to feel Herb's presence and contributions within and outside the TASH community.

While it is not possible in this limited space to go into sufficient detail as to all of the ways Herb has influenced our thinking, we have provided a snapshot... sound bites if you will ... as to the impact Herb has had on our lives, the field of disabilities, and society at large

> *"Trying to distill the impact that Herb has had on the field into a few brief statements is somewhat like trying to interpret Dicken's A Christmas Carol by simply saying that we can all change for the better when we listen with our heart. On a personal note, I most miss Herb's fast, and at times lashing out, sense of humor. While I came to expect a variety of interesting comments from Herb, he never failed to catch me off guard on more than one occasion. In the larger scale of things, Herb's insights on the relationship among science, politics, and the human condition have had — and will likely continue to have — a lasting impression on the field. In particular, Herb's teachings have helped me to better understand how technologies can never, and should never, become the exclusive focal point of our efforts in supporting people who present challenging behavior. Or, as Herb would say "the criterion for success is not just about results . . . it is also about how we stay with people while they change and grow."* — Tim Knoster

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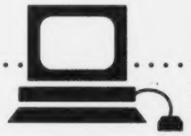

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
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- **Don't forget to visit TASH's web site at http://www.tash.org**

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VIEW FROM A BOARD MEMBER

Continued from page 2

"After several attempts at previous TASH conferences to hear Herb speak but failing to get near the door, I sat through a session in which I had absolutely no interest but it happened to precede Herb's session, guaranteeing me a seat. Herb was not a "topic" person like so many of us. He embodied the soul of what drives worthy disability advocates. He spoke about people with disabilities with unmatched respect and held them in such an honorable light that I'm not sure anyone can follow in his footsteps. He didn't just speak about the importance of community, he cherished it for the struggles and the celebrations that make it strong. I am proud to have known him."

— Donna Gilles

"Other than listening to Herb speak at various conferences, I never knew Herb personally. Yet he managed to challenge my thinking and beliefs perhaps more than any other colleague. At times he infuriated me. Most of the time he frustrated me as I failed to understand or to be open to the meaning of his messages. I had difficulty grasping how supports for people with complex needs could be translated into "listening" and "nonhierarchical relationships." But life is filled with personal ironies and important lessons. For me, one irony became apparent as I neared completion of a qualitative study that explored the experiences and perceptions of teams who supported adults with significant behavioral challenges in community settings. As noted by a few of my colleagues, I went into the project describing supports in terms of technological interventions and came out 'sounding like Herb Lovett!' It's not that I now reject systematic interventions. Rather, I've broadened my perspective. I've come to understand the importance of personal relationships—how trust, mutuality, and the willingness to be open to another's needs appear to be the driving force behind truly meaningful and effective supports for people who have been devoid of close personal relationships in their lives. I now understand, as emphasized by Herb, the significance of relationships as both the context and primary goal of positive supports."

— Linda Bambara

"They say that you are only a true expert when you can influence change in your own backyard. A large backyard New England is, but Herb managed, despite his extraordinary travel schedule, to raise our collective consciousness as well as to provide a personal note of camaraderie. Debbie Gilmer remembers how she and a mutual friend approached Herb at a supported employment conference as he was sitting on the floor with his laptop. Herb immediately jumped up to welcome the young man and within moments, the two of them were sitting on the floor, laughing and typing back and forth to one another in their effort to get reconnected. John Butterworth recalls that, despite being near-neighbors, his contacts with Herb occurred almost entirely in airports — most recently in Ohio, talking about systems change and person centered planning as Herb tapped away on his laptop. Liz Obermayer tells us, 'I knew Herb from many different national events. He was a great friend to the national self-advocacy movement and a friend in general to all. We will miss him.' And countless other New Englanders, who did not have the chance to approach this man on a personal level, thoroughly enjoyed being squashed into standing room only workshops to hear Herb using a lively banter sprinkled throughout with stories and "Herb-isms" that had the audience in stitches — and had them leaving with new insights that only Herb could instill.

— Linda Rammler

In light of these and countless other perspectives on Herb's contributions, it is with a sense of purpose that we encourage you to read, reflect, discuss, and share this edition of the TASH *Newsletter* with your friends and colleagues. As Herb noted in his most recent book, "real behavior change comes from a relationship; the more serious the need for change, the more serious this relationship needs to be." Each of us can attest to changes we have experienced in how we approach interactions and problem solve with one another in relationship to Herb's work over the years. It is our hope that collectively, we in the TASH community will continually expand our abilities to listen with understanding to ourselves and one another as we move forward in our advocacy efforts.

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From the Executive Director

BY NANCY WEISS

I write this a few days before staff leave for the conference in Seattle. Like many of you, I approach every conference with a real sense of excitement but I'm anticipating this year's conference with a sense of disbelief as well. It's hard for me to imagine a TASH conference without Herb Lovett there. As many of you know, Herb died in a car accident last March. Herb was a mentor to me — as he was to many others across the country. This issue of the Newsletter is dedicated to Herb. Herb is also the recipient of the 1998 TASH Positive Approaches Award.

Herb's partner, Michael Dowling, and some of Herb's friends have established a fund and an annual award in Herb's memory. The award is called the "Rabbit Award". Herb closely identified with rabbits – animals known for being fleet of foot, able to make great leaps and creatures accomplished in their ability to call down fears and face them. The Rabbit Award is a cash award to be presented to someone who has "made the leap". Nominations and self-nominations are being sought. For more information about the Rabbit Award, see page 20.

One of my jobs before coming to TASH was running a project in which behavioral staff worked with parents, teachers, direct care staff and others to support people with seriously challenging behaviors in their homes, schools and communities. I will never forget a lesson I learned from Herb during one of his many visits to help us assure we were doing the right things to support people that presented tough problems. He said, "The real key is this; you have to pretend that in the end, all the people for whom you provided behavioral supports are lined up at the pearly gates. Some portion of the people you supported come up and shake your hand and thank you for the support you gave. They tell you about the positive ways in which the support you provided affected their lives. Then there's the other group – they approach you with their hand out, too – but rather than shaking your hand, they haul off and slug you." Herb went on to assure us that we were never going to end up with everyone fitting into the first group; but that the whole focus of our work with people had to be aimed toward improving the odds.

I can't help but imagine Herb up there, with his impish grin, and a lot of hands to shake. As will become clear as you read this issue, Herb left an important legacy in the many souls he touched here on earth.

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Solutions of the Head, As Well As the Heart

BY SUSANNAH JOYCE

Since last March when, as one mutual friend has phrased it, "Herb left," I've written several pieces about him for various journals and newsletters. It still feels strange to compose articles about a dear personal friend who was also a public figure, and who continues to have a wide and powerful impact among his professional connections.

I think we all search for meaning when someone we're close to dies, but it feels like a particular responsibility to learn from the life of a person like Herb, who touched so many others during his career. His talents and interests were so rich and varied that it will take us a long time to appreciate his entire legacy. One of his qualities that has been particularly important for me is the way in which he kept deepening his work of understanding others by including more of the personal — through his own example, as well as by extending invitations to colleagues to do the same.

Back in the 1970s the women's movement used to refer to something called, "the click" — that seemingly sudden realization or epiphany that shifted one's consciousness, causing an awareness that there was, indeed, a problem, a lack, a need for change. For Herb, I think that one of those "clicks" in his own work came when he was writing behavior plans in an institution for people he wasn't even required to see. A thought occurred to him: Why not meet the person over whose life he had so much power and control? This impulse appears so logical, even obvious, but at that time and place it was considered not only unorthodox, but extremely ill- advised, and its rejection led Herb to question more and more of the attitudes and approaches used in supporting people labeled with challenging behavior.

At the basis of this shift was a straightforward but profound assumption: that people who need some extra help would appreciate the same respect and opportunities for power and choice as those offering the assistance, and they would respond — did respond — in ways similar to how most of us react when we are treated with compassion instead of control.

It is one thing to be willing to treat other people as we would wish to be treated, to extend courtesies and kindness to those we have defined by their difference. Herb invited people to take the next (often frightening) step in this journey by suggesting that we also needed to look at our own difficulties and pain if we were to provide genuine help to people in distress.

"What is our brokenness?" he asked in his TASH session in Chicago some years ago. Herb had come to realize that until we own and understand the ways in which we have been hurt and how we have been shaped by these experiences, that we are withholding the parts of ourselves that most deeply inform our capacity to be of service.

❦

He valued clinical expertise in himself and in others, but his insistence on the presence of some mutuality and good will as the foundation for change has been an invaluable contribution to our field.

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People who have attended Herb's trainings will recall the process he often used to help others make connections between incidents and feelings from their own lives and the behavior of those they supported. Conversations would be initiated by asking staff to identify some of the behaviors that puzzled them and what they were currently trying to do to help in these situations — fairly safe territory. The next two questions, however, would always take the group right to the heart of things:

> "When have you behaved
> in a similar way?" and
> "What were your good reasons
> for doing so?"

Through hosting Herb in many locations and facilitating with him as we came to know each other better, I saw how countless groups of people were helped by his process, to make a fundamental shift in attitude. As they considered what their own motives had been for some sort of self-injurious action or "attention-seeking," the realization would come that people with the label (or "severe reputation," as Herb called it) of being challenging might also have reasons for how they acted. Once staff and families were able to accept that there was some sort of logic associated with people's puzzling behavior, they became much more open to problem-solving with them instead of imposing controls over them.

After I had seen the powerful effects of these discussions I asked Herb if he would do something similar, but with the focus on how people providing support could gain an understanding of one another's difficult behavior. Like many other consultants I had noticed a number of situations where problems among professionals or between families and staff created major obstacles to the support given to people with disabilities.

Herb's response was to invite me to work with him to create and facilitate this workshop. We used a process similar to his usual one to help people explore

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Solutions of the Head, As Well As the Heart

Continued from page 5

> **The atmosphere Herb inspired was not some manufactured attempt at "group therapy"; it was based on honesty, respect, and the assumption that each person in the group had power if they wished to claim it and use it.**

some of the "good reasons" why colleagues, supervisors and non-paid supports could be critical, untrustworthy, or uncooperative.

One of the very powerful questions that Herb would pose to people who were puzzled over the actions of someone with a disability was "Who loves this person?" When confronted with the reality of people's lives, staff too often had to concede that no one loved the person, and that helping them develop some relationships would have to be one essential part of any future support.

By asking that same question, "Who loves the person?", regarding a manager or someone else providing support, staff and family members were able to gain new insights about those with whom they worked. It was often something of a revelation to consider that the director of an organization, a psychologist, social worker, or parent-advocate might feel as universally disliked or even unloved as someone labeled disabled. Pondering new possibilities for why colleagues behaved as they did allowed people to let go of some of the blame and hurt and extend greater patience and willingness to improve these working relationships.

It is important to note that none of these discussions, whether around people with disabilities or co-workers, was based on any glib belief that everything would resolve itself if people just loved one another enough. Herb would often remind everyone that we weren't in Mr. Rogers' territory, where good relationships would automatically result in "...a beautiful day in the neighborhood." He brought a practical, commonsense approach to problems, exploring solutions of the head as well as those of the heart. He valued clinical expertise in himself and in others, but his insistence on the presence of some mutuality and good will as the foundation for change has been an invaluable contribution to our field.

Herb worked hard to live the beliefs he spoke about, and frequently shared struggles and insights from his personal life in ways that enlightened rather than imposed upon his audience. He kept pushing the boundaries of what were "acceptable" areas to explore if we were to broaden and deepen the context in which we considered challenging behavior. He was quick to see the sense of defining change for people with disabilities as part of a larger social justice movement while, at the same time, emphasizing the connection between the political and the personal, even spiritual, nature of this work.

When we worked with people at The McGill Summer Institute in Montreal each summer, our group had two weeks together to reflect on their own difficulties and fears within the safety of the course's larger focus on challenging behavior and people with disabilities. For a small minority each year the prospect of looking beyond the problems of those they served to include some examination of issues about where they worked, with whom they worked, and some of their own concerns, was just too terrifying. But most people went home from these gatherings as changed beings, as did Herb and myself each time, because we had all shared a haven where we could peel back a few more layers if we chose, and grow a little in tolerance and understanding. The atmosphere Herb inspired was not some manufactured attempt at "group therapy"; it was based on honesty, respect, and the assumption that each person in the group had power if they wished to claim it and use it.

Based on the quality of connection that occurred in our group each year in Montreal, and on his own strong interest in the spiritual, Herb initiated the idea of retreats where people could discuss their own experiences of service, spirituality and leadership. We facilitated these gatherings with our friend and colleague from England, Joe Whittaker, and learning about others' personal and spiritual beliefs and how these values influenced and sustained their work offered yet another way to strengthen professional commitment and deepen that network of collegial relationships.

In trying to gain some insight into what we can learn from Herb's life and his work, we certainly need to consider his accomplishments. We must also reflect, however, on the person he was. If I were to try to summarize the importance of what he did, I would say that he helped people to integrate a more holistic approach to supporting people and to understanding challenging behavior, based on mutuality of relationship, compassion and commonsense.

It was the kind of person he was, however, that allowed him to have such a great impact. His invitations to people to connect more deeply with the personal and spiritual in this work and his willingness to be open in his own struggles and progress in these areas could have been perceived as superficial or self-serving in someone less genuine than Herb. He was the first to admit how frequently he fell short of his own aspirations for tolerance. But if he had already mastered all of the qualities he sought or if he had been less forthright about the problems he faced in comprehending difficult behavior in himself and in others, people would not have been drawn to him as they were. Herb's ideas and beliefs were grounded in humility, humor, empathy, and a fineness of spirit that warmed us and inspired us to try a little harder, as he did.

In our attempts to continue his work I believe our most important lessons present themselves less in the doing than in the being. If we can find some of the courage he showed to keep uncovering and giving from our authentic selves, and if we have a real willingness to bring generosity and graciousness to our struggles with everyone's "difficult behavior," then we will certainly honor Herb's memory as well as his vision, and create some significant social change at the same time. How he would love that!

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Who Will Be HERB LOVETT Now?

BY MAYER SHEVIN

Like many other members of TASH, I knew and admired Herb Lovett for many years, although our paths crossed infrequently. Despite the rarity of those treasured interactions, Herb was a fixture in my life; he could be counted on to say those things that most needed to be said, to describe most clearly the Emperor's lack of clothing, and to say precisely where real dignified garments for all our fellow humans might be found.

When Herb died, I spoke with many people who knew him. We shared our personal loss, and found we had a common reaction: "Who will be Herb Lovett now?" We could not envision doing our work without his wise, passionate voice speaking out about the injustices done to our friends in the name of benevolence. We knew we would feel the absence of his clear perspective that we are all fellow travelers, figuring out the hard parts of life together.

Fortunately, Herb's legacy includes a couple of very clearly written instruction manuals on how to carry the work forward. His books, *Cognitive Counseling and Persons with Special Needs* (Praeger, 1985), and *Learning to Listen* (Brookes, 1995), both provide enormous insight into how to do this work of ours - our real work - that of sharing our lives with others across our real and imagined differences.

There is a passage by Walt Whitman that seems to describe Herb very well. It reminds us that, despite our loss, we are all empowered to continue the work that our friend left behind. Whitman was talking about the source of poetry that exists within each of us. It resonates with Herb Lovett's ability to speak to the potential for understanding and connection that each of us holds.

> *This is what you shall do: Love the earth and sun and the animals, despise riches, give alms to everyone that asks, stand up for the stupid and crazy, devote your income and labor to others, hate tyrants, argue not concerning God, have patience and indulgence toward the people, take off your hat to nothing known or unknown or to any man or number of men, go freely with powerful uneducated persons and with the young and with the mothers of families, read these leaves in the open air every season of every year of your life, re-examine all you have been told at school or church or in any book, dismiss whatever insults your own soul, and your very flesh shall be a great poem and have the richest fluency not only in its words but in the silent lines of its lips and face and between the lashes of your eyes and in every motion and joint of your body... The poet shall not spend his time in unneeded work. He shall know that the ground is already plowed and manured...others may not know it, but he shall. He shall go directly to the creation. His trust shall master the trust of everything he touches... and shall master all attachment.*
>
> (Walt Whitman, Preface to Leaves of Grass, 1855.)

Herb Lives in Los Angeles

BY JEFFREY L. STRULLY

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> **Herb was a wonderful, thoughtful, and masterful educator, thinker, and mentor. He helped us in so many ways, but more than anything he was a friend.**
>
> ★ ★ ★

Herb's not gone. He can't be. He has not completed his contract with our agency. I have a signed document stating that he would provide on-going consultation and support to us as we move forward with our journey of supporting people in valued ways. He owes me several reports, so you see he can't be gone. He continues to live daily in Los Angeles in the way we think about the people we support, their lives, and how we live our lives. So you see Herb is not gone — at least to us.

For the past six years, Herb spent a considerable amount of time working with our agency and the people we support. As everyone knows, Herb was one of the most of the thoughtful, funny, and weird people I have ever known. Herb worked hard at pushing us to think outside of the box. Time and again we would get caught up into trying to think simply about something or looking for easy solutions for complex problems. Over and over, Herb would push us to see the humanity in people and not get caught into the labels, diagnostic categories, and all of the stuff that surrounds people who challenge us. He helped mentor many of our staff who have come to be "Herb look-a-likes." He loved spending time with us - because we had so many unique people who worked for us that he actually fit in. When he stayed with us, he would want to stay in the cheesiest motels and local neighborhoods. That was Herb.

When I was looking for an assistant executive director just before his tragic and untimely death, he referred to me Jopie Smith. He told me that she had to get out of Texas and from what I can tell that made perfect sense. Obviously, after years and years of living in Texas she finally came to her senses and moved to Los Angeles. Herb told me she would fit in and that she would bring a nice southern personality and approach. He was right. But Herb was right lots of times.

Everyone knows that Herb had a biting sense of humor. He could attack people and they wouldn't even know it. We had such a good time poking fun at our colleagues. It was one of the things we enjoyed so much — making fun of our colleagues and, more importantly, our friends. With a laser like approach, he could rip apart a fellow colleague. How wonderful.

Herb was a wonderful, thoughtful, and masterful educator, thinker, and mentor. He helped us in so many ways, but more than anything he was a friend. I will miss Herb and I know that my colleagues at Jay Nolan will miss him, as well. However, he's not gone. He continues to live in our hearts as well as in our heads as we continue the struggle to build communities that more than accept, but embrace diversity and celebrate each and every one of us.

So Herb, take care and keep watching over us and continue to mentor us. We have lots to do before the dreams that we want to see happen for the people we support are realities. We need your help, so don't be far away!

The Special Education Service Agency - Anchorage, Alaska

SESA currently has a vacancy for an Education Specialist in the following specialty area. For more information about our organization, visit our website at http://www.sesa.org.

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(5) Current knowledge of assistive technology options for students;
(6) Ability to work collaboratively with team members, and,
(7) Excellent health and the ability to travel extensively and independently in rural/remote Alaska.

Preferred Experience

Direct experience with students with multiple/significant disabilities across age ranges - preschool through high school - and various ability levels; Providing training to professionals and/or paraprofessionals; and Inter-agency networking and collaboration.

Contact: John Lund, Program Administrator — Special Education Service Agency
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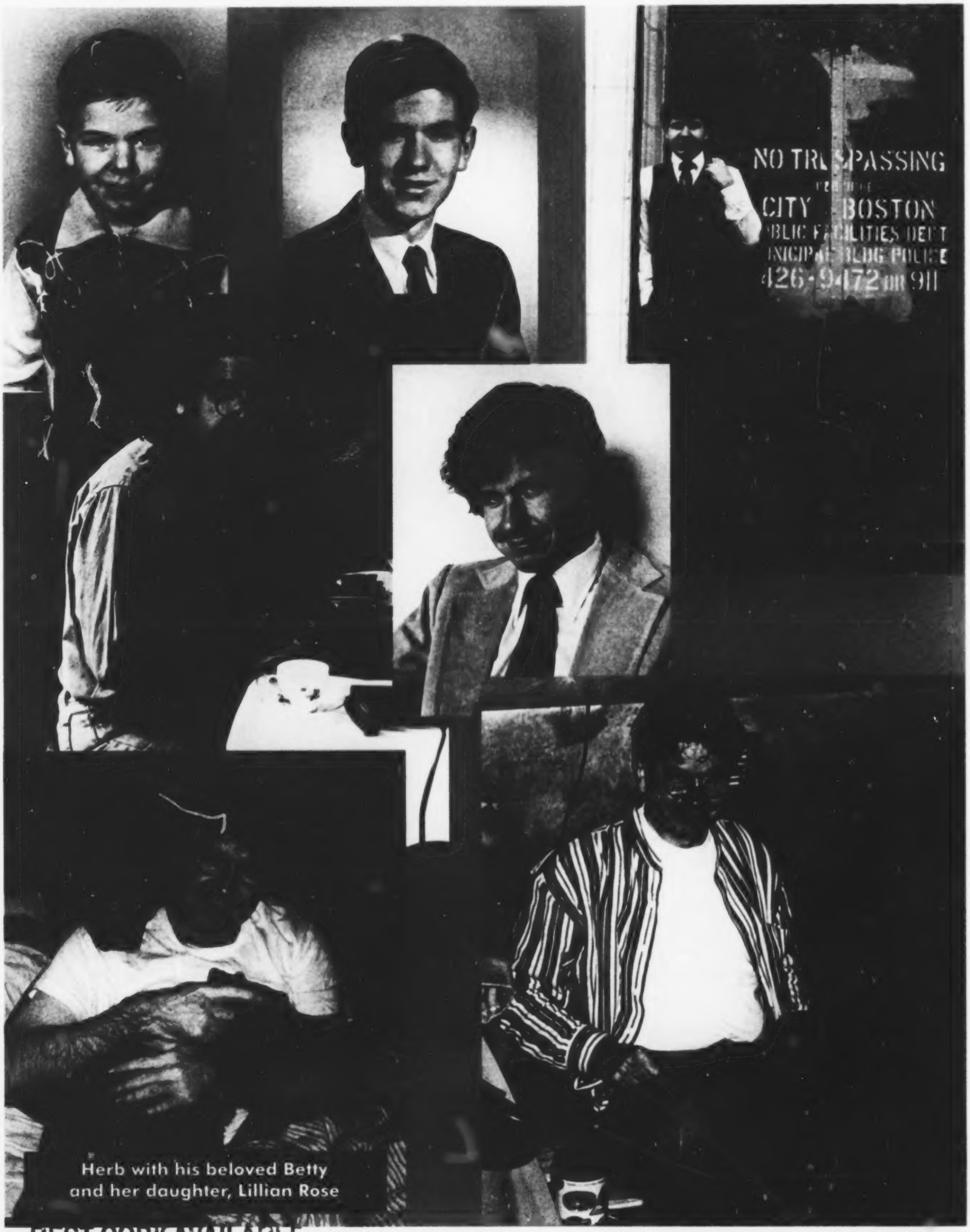
HERB LOVETT — THROUGH THE YEARS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Herb with his beloved Betty
and her daughter, Lillian Rose

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The Top Ten Reasons I loved and will miss Herb Lovett

10 Though many us always suspected, he was the first to actually prove that bowling causes mental retardation.

9 He helped us understand that allowing people to have breaks and apologizing about our failure to support them are more appropriate than ignoring and timeout.

8 He showed us the utter futility of using token rewards for people who don't live near a bus line.

7 His "Miss Manners" training exercise taught us to question why there is such a big difference between what we want, what works for us and what we do to "them."

6 He taught me how to take a perfectly laundered shirt, roll it up in a ball and achieve the "Lovett Look."

5 He created work for me. He would go someplace and pretty much tell the truth, at least his version of it. Later, the people who invited him would call me and say "Herb was great, he changed our thinking and we are excited about the potential for change, but…all the psychologists left the training session during the morning break. Could you come help us get them back?" Not being committed so much to the truth, I would answer, "of course."

4 He was the best person ever to share professional gossip with.

3 He liked the same people I did, which gave me more confidence in my own judgments.

2 His profound humility, evidenced by his taking on all of behavioral psychology and spending his spare time correcting flaws he discovered in the works of Beethoven.

1 Listening to him and reading his books helped make me a better person and better at my work.

— Wade Hitzing

Dear TASH:

I don't know if this is the venue at which you wanted to receive tributes and remembrances on the life and work of Herb Lovett, but I thought I would try anyhow.

Not long ago I received my *Newsletter* and heard the terrible news of his much too early loss. After spending years working for persons with autism and other developmental disabilities, I am currently working for persons living with psychiatric disabilities. And still, on a regular basis, the many things learned from Dr. Lovett when I was a very young practitioner come into play: insistence on a positive approach to our work with persons and a recognition of the right to individual choice come to mind, among many others.

While I employ a lot of these wonderful lessons in my current work, the one thing I have "stolen" from him which I think has the quickest and most immediate impact in training is his on-target labeling of do-nothing day programs as "Day Wasting Programs."

I do a great deal of training for practitioners and administrators of mental health services all around the country, and believe me, the term still fits a vast majority of federally funded programs for people who are living with psychiatric challenges. These "programs" are places where the only option people have is to sit around, drink coffee, watch TV, and learn to have dreamless lives. The polite name is usually Partial Hospitalization programs, sometimes they are called Day Treatment Centers.

I trust that Dr. Lovett would enjoy the immediate response I get as I start into my discussion of these programs and call them what they are – it never fails to start a dialogue! Some would call it an argument. Whatever people choose to call it, it gets folks thinking about what is right and what is fair and what our efforts are supposed to be all about.

I am very, very grateful to have had the opportunity to have listened and read and benefited from the gift that was Herb Lovett. All of us who remain must make sure that his work and his legacy live on in the efforts of the years to come.

Dr. Kate R. Donegan
Director of Services
Matrix Research Institute
Philadelphia, PA

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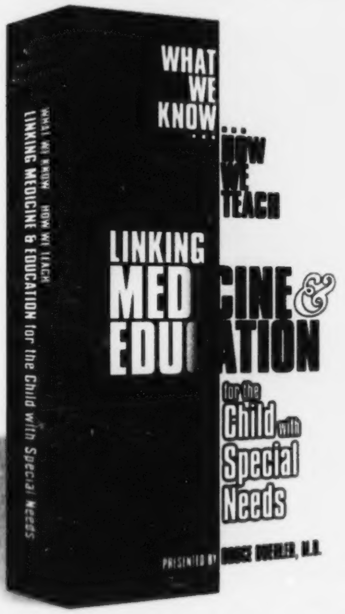
INCLUSION

WHAT WE KNOW...

...HOW WE TEACH

NEW! 1998 VIDEO


WHAT WE KNOW... HOW WE TEACH
LINKING MEDICINE & EDUCATION for the Child with Special Needs
WHAT WE KNOW
...HOW WE TEACH
LINKING
MEDICINE &
EDUCATION
for the Child with Special Needs
PRESENTED BY BRUCE BUEHLER, M.D.

Linking Medicine & Education for the Child with Special Needs

BRUCE A. BUEHLER, M.D.

Across America there is an ever increasing number of special needs children in our schools. Children whose medical conditions and instructional demands are closely linked. Whether it is medication, physical or occupational therapy, or prescribed behavioral interventions, these children present special healthcare needs which educators need to know in order to teach them well.

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STANDARDS

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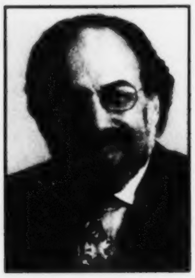
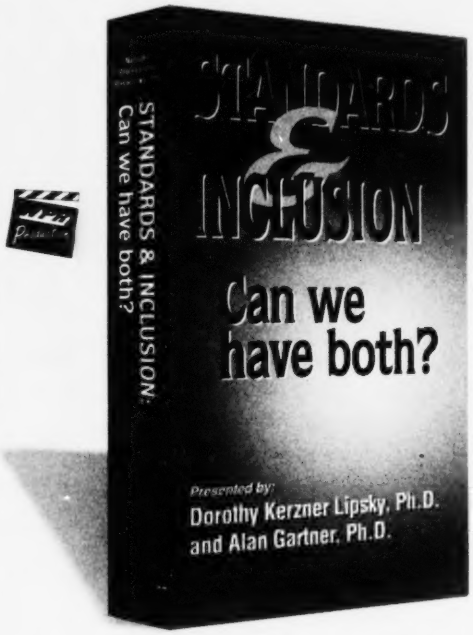
The move toward higher standards in our nation's schools has raised a major dilemma for educators committed to the inclusion of students with disabilities. How can these students truly succeed in a learning environment where academic standards and formalized testing are increasing?

DOROTHY KERZNER LIPSKY



ALAN GARTNER

Dorothy Kerzner Lipsky and **Alan Gartner**, from the National Center on Educational Restructuring and Inclusion at the City University of New York, address many of the critical issues facing educators who are supporting students with disabilities in inclusive settings.



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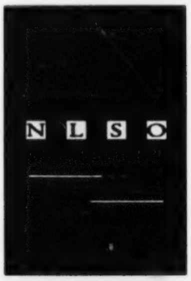

ABOUT THE AUTHORS: ***Dorothy Kerzner Lipsky*** *is Director of the National Center on Educational Restructuring and Inclusion, and* ***Alan Gartner*** *is Dean for Research. Both are at The Graduate School and University Center, The City University of New York.*

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Shipping & handling: Add $4 per book; $5 per video. Orders of $50 and above add 10%. Canada add 20% to all orders.

Radical Heart, Moderate Mind:

A Perspective on Inclusion

BY PETER V. PAUL

Remember only this of our
hopeless love
That never till time is done
Will the heart and the fire of the
mind be one.
— Dame Edith Sitwell
(1887-1964)

One of the most popular questions that some of my students like to ask me is: What do YOU think of inclusion? Typically, any response to that question is complex and detailed; however, these students expect something 'more' from me. For sure, they expect to hear three 'voices', at least: (1) a personal one based on my 'condition'—a profound bilateral hearing impairment (i.e., deaf with a lower-case d); (2) a professional one representative of my scholarly views regarding deaf and hard of hearing children; and (3) a familial one representative of my feelings as a father of a son with Down syndrome (now 7 years old), who also has autistic-like behaviors and, possibly, apraxia (aphasic type of problem). Given the above, I always ask the students whether they expect to hear one, two, or three 'perspectives.' To my surprise (well, not really), nearly all of them select the two or more categories.

You might inquire: . . . Does inclusion work? . . . for a number of us the question is: what can we do to make inclusion work?

In essence, I have only one voice, influenced mostly by my role as a father, and it sounds like this: "Wearing my critical metatheoretical lens and reflecting on diversity and equity issues, I feel that we need to do our best to include everyone in all aspects and institutions of society such as the community, education, business, and so on. I am aware that this 'radical inclusion' approach will require many resources, a great deal of energy, and an on-going commitment, especially for certain individuals (i.e., individuals who are deaf, blind, or who have significant physical, emotional, and/or cognitive 'conditions'). For many of these 'certain' individuals, inclusion—especially full inclusion in general-education classes in schools—might be very unrealistic, undesirable, and not very cost effective. Nevertheless, I still feel that we should proceed as fast as we can with full inclusion as our guiding light for most of these individuals. This is what I called my 'radical heart, moderate mind' approach. Yes, it is what I want for myself, most deaf and hard of hearing students, and my son; and, yes, it is more radical than moderate.

No need for my readers to throw cyberspace tomatoes or pull out their hair although I admit that my students do mutter — 'he's doing it again.' They are referring, of course, to my incessant penchant for critical metatheorizing. However, the 'radical heart, moderate mind' response is based on my scholarly conclusion that inclusion requires a critical (e.g., via critical theory) resolution because it cannot (should not) be resolved 'empirically' (e.g., via science). I think I just felt a few knee-jerk reactions to that statement. You might inquire: Do you mean that we cannot or should not investigate whether inclusion is 'effective'—that is: "Does inclusion work? Oh, you can, but only if everyone wears the same pair of lens and are interested in the way this question is worded. I am not, and neither are many other parents and professionals. In other words, for a number of us, the question is: What can we do to make inclusion work?

As most of you know, the Individuals with Disabilities Education Act of 1990 (IDEA) (PL 101-476), which was reauthorized in 1995, dictates that every school-age child with a 'disability' (e.g., blind, deaf, etc.) shall have the right to a free and appropriate public education in the least restrictive environment (LRE). The interpretation of the word free seems to be widely accepted; that is, educational services should be provided to meet the individual needs of the students at no cost to the parents. On the contrary, there is much ongoing, acrimonious debate on the interpretation

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of the word appropriate. This debate focuses on such issues as the contents and practices associated with instruction, curriculum, and assessment as well as the manner in which educational services, including ancillary services (e.g., speech pathology, physical therapy, etc.) should be provided. In addition, even the location at which services should be rendered, that is, the LRE, does not have a universally accepted definition. Nevertheless, there is a growing consensus that 'special-education' is not a place. Rather, it is a rendering of services to 'whatever place'—and, this 'place' seems to be the environment which contains, at least, individuals without 'disabilities'. Thus, in one sense, the LRE can be wherever you want it to be. However, with respect to diversity and, possibly, equity, the LRE cannot be a separate, specialized setting, which houses only individuals of a particular gender, race, ethnic group, religion, or disability. Oops, I think I see some more cyberspace tomatoes coming my way.

Let me continue. As I mentioned, it is often stated that services should be provided within placements involving non-disabled peers. The law, however, does allow for a full continuum of services. That is, placements can include general-education classrooms, special segregated classrooms, homes, or clinics and hospitals. The placement decision is the task of the student's education team members (e.g., Individualized Education Plan [IEP] team, multifactor evaluation team, multidisciplinary team, etc.), who attempt to describe the optimal educational conditions for a particular student relative to the terms appropriate and least restrictive environment. In making a decision, members of the school team are often influenced by what can be called the 'comparison' lens (e.g., see Paul & Ward, 1996) or the 'readiness' lens in which there is an attempt to select the 'best' setting based on achievement and/or socialization data on the student. They might also consider other issues such as existing services, current placement procedures, or interpretations of the legal parameters of IDEA (e.g., Osborne & Dimattia, 1994). On the other hand, many parents, including the present writer, are influenced by what can be called the 'ethics' lens (Paul & Ward, 1996), which is, typically, more oriented toward value-based and successful outcome measures within an inclusive setting, namely, a setting with nondisabled peers.

These two broad paradigmatic lenses of inclusion—comparison and ethics—can be 'deconstructed' from a critical analysis of several prominent publications (e.g., Kauffman & Hallahan, 1995; Stainback & Stainback, 1984; Stainback & Stainback, 1992). In fact, these two broad labels seem to capture much of the information on inclusion in the theoretical and research literature. Of course, this is my critical metatheoretical assumption.

. . . many parents, including [this] writer, are influenced by what can be called the 'ethics' lens . . . which is typically more oriented toward value-based and successful outcome measures within an inclusive setting, namely a setting with children without disabilities.

Research scholars who favor the comparison paradigm conduct research (mostly quantitative) designed to answer the question: Does inclusion work? Typically, this involves the comparison of social and academic performances of students in one setting with those of statistically-matched counterparts in another setting (e.g., see discussions in Bilken & Zollers, 1986; Fuchs & Fuchs, 1994; Wang & Walberg, 1988). The main goal is to determine whether there is a statistical difference relative to the type of setting. That is, which setting (or conditions within the setting) is responsible for the higher performances? Within the comparison paradigm, researchers need to ensure that variables are statistically controlled so that the effects of main factors, for example, achievement or socialization, can be evaluated. Obviously, making these comparisons or interpreting the results is not a piece of cake. Indeed, some scholars have argued that it is unrealistic or an oversimplification. Still others have argued that it is really not possible to reach a widespread consensus based on empirical findings alone (e.g., see discussions in Paul & Cartledge, 1996).

For scholars within the comparison paradigm, the placement of a 'special-education' student in inclusive settings should be contingent upon the student's ability to meet certain, minimum social and academic criteria, and whether an individual's needs can be met in such a setting. So, in general, the least restrictive environment and/or the most appropriate placement for a student is an individualized decision based on careful examination of social and academic criteria and the individual's

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present levels of performance. This approach to inclusion might best be described as "cautious and individualized." There is also much doubt that general education will ever be in a position to handle effectively students with diverse characteristics, especially students who are deaf, blind, or have significant and/or multiple disabilities (e.g., see discussion in Kauffman & Hallahan, 1995). Consequently, these scholars argue that separate settings are not only equal to integrated settings but also, in some cases, separate settings might be better and preferable.

Scholars who favor the ethics paradigm argue that inclusion is predominantly an ethical and diversity issue (e.g., see discussions in Stainback & Stainback, 1990; Stainback & Stainback, 1992). The most important question is: What can we do to make inclusion work? Within the ethics paradigm, the goal is to ensure the success of children with special needs (indeed, all children) in typical, general-education environments. Proponents of the ethics paradigm assert that all individuals should be treated with dignity and have a moral right to be included in the mainstream of general education (e.g., Biklen, 1985; Gartner & Lipsky, 1987; Stainback & Stainback, 1990). Stainback and Stainback (1990) have remarked: "No one should have to pass anyone's test or prove anything in a research study to live and learn in the mainstream of school and community life. This is a basic right, not something one has to earn" (pp. 5-7).

> ***"No one should have to pass anyone's test or prove anything in a research study to live and learn in the mainstream of school and community life. This is a basic right, not something one has to earn."***
>
> **Stainback and Stainback (1990)**

To address the question, What can we do to make inclusion work?, educators (and others) need to remove a few barriers to 'effective' inclusion. With respect to the bureaucratic organization of the schools, some barriers are "fixed" curricular and instructional practices geared to "average-performing" students, lack of collaborative structures involving classroom teachers and relevant support personnel, standards imposed by a centralized administration (e.g., national guidelines, state mandates, etc.), and funding practices (e.g., see Fagel-Wilson et al., 1993; Skrtic, 1991). In my view, the biggest barrier is the dual system of education—general education and special education—as can be seen in the existence of separate university preparation programs, funding systems, and administrative functions and rules.

Focusing on inclusion in education, I believe that most parents are concerned with discrepancies between the outcomes they desire for their children and the outcomes that they believe will occur in a particular setting. Parental perceptions of what is best for their children are probably influenced pervasively by their perceptions and satisfaction with the educational services actually provided for their children. The crux is this: If parents (and, if appropriate, their children) were satisfied with the rendering of services in an inclusive setting, then they will be more apt to select this setting over any 'segregated' setting. Parents need to be assured that their children will be reasonably accepted in these inclusive classrooms and not be subjected to overly unreasonable physical and mental abuse (e.g., York & Mundidor, 1995). In my view, these parents are most concerned with the question: What can we do to make inclusion work for my child? For me, and many other parents, this is the 'question' that should be addressed for children with special needs, indeed, all children.

With all due respect to my university students and to my readers, I am 'doing it again' because the framing of the question is pervasively dependent upon the critical perspective (i.e., paradigm) of the framer. I prefer an inclusive frame and want to know—what can we do to make it work and will we do it for everyone, as much as possible? Now, before anyone throws the next batch of cyberspace tomatoes, consider these critical musings. I am not against the creation and support of 'separate or special educational institutions' because these settings play an important role for individuals who attend them for self-concept, self-esteem purposes or who attend them out of choice or for the best opportunity to reach their 'full potential.' Granted, it is difficult at times being a woman, a member of an ethnic or minority group, or an individual with a disability.

I often wonder, though, if it is possible to create an inclusive, multicultural world by being educated only in these settings. Oh, I am certain that it is somewhat possible, however, given the little that I know about 'contact theory' and its variations (Allport, 1961), it seems to me that we must interact with others who think, look, smell, act, and feel differently from us. For me (perhaps, unfortunately, for me), a multicultural, inclusive world is

Continued on page 19

> **For me, a multicultural, inclusive world is not really possible through the cognitive avenue only. That is, you cannot just 'read and discuss' about others. You have to study, work, live, eat, talk, etc. with them. The more this happens, the more likely one can develop an appreciation and, hopefully, acceptance and understanding of the diversity of the human race.**

Radical Heart, Moderate Mind

Continued from page 18

not really possible through the cognitive avenue only. That is, you cannot just 'read and discuss' about others. You have to study, work, live, eat, talk, etc. with them. The more this happens, the more likely one can develop an appreciation and, hopefully, acceptance and understanding of the diversity of the human race. And, who knows, maybe this will go a long way in resolving some of our equity issues.

Ah, the joys of critical metatheorizing and the pains and frustrations of the slow, tedious progress toward the utopia of social justice.

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The Herbert Lovett Memorial Fund
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"In the earlier part of this century we believed that the new behavioral sciences, with a cunning scheme of rewards and punishments, would remove difficult behavior effortlessly. I think that dream is dead. I hope so. I hope that we've come to the point in our history where we have started to recognize that: the end point of pure thought is probably death; that we are not going to think our ways out of these problems; and that we require a new respect for the irrational, the intuitive and the felt. we are discovering that we need people who step out of the mode of what we created....to remind us who we are and who we need to be for one and other."

Herbert Lovett 1995

Herb had a strong tie to rabbits in his life. The rabbit is know for its ability to procreate, its fleetness, its ability to make great leaps, and its ability to call down its fears and face them.

On March 20,1999, the **Herbert Lovett Memorial Fund, Inc**. will be presenting its first **Rabbit,** a cash prize, to a person who has made the leap. This award is open to all. We are also looking for **donations** to make this a sustainable fund. For more information on the **Herbert Lovett Memorial Fund,** write to either address below.

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FACULTY POSITION

Eastern Michigan University's Department of Special Education invites applications for a tenure-track assistant professor position - available Fall 1999. Responsibilities include teaching undergraduate and graduate courses; advising students; supervising student teachers; conducting scholarly and service activities; and working collaboratively in a team situation with a field-based study program.

Qualifications: Master's plus teacher certification and endorsement to teach students with mental retardation, both elementary and secondary preferred. Minimum of five years teaching experience, including at least three with students with mental retardation. Preferred: Ph.D. or Ed.D; teaching experiences in a variety of settings including inclusion settings, unified systems, resource rooms and/or as teacher consultants; skills in using technology with students with mental retardation; effective interpersonal skills and ability to work within a collaborative team; documented evidence of effective collect teaching and/or with adult learners.

Review of applications will begin January 15, 1999 and continue until position is filled. Send letter of application, resume, transcripts and three current letters of recommendation to Position F9926, 202 Bowen, Eastern Michigan University, Ypsilanti, MI 48197.

We encourage applications from women and members of minority groups. AA/EOE.

A Tribute to Herb Lovett:

TEACHER - MENTOR - FRIEND

Herb Lovett, Ph.D., was a man of great courage, conviction and extraordinary caring. He was a friend to many, especially people with disabilities and their families. And he was a special friend to the Autism National Committee.

I met Herb in the mid '80s after the publication of his first book, which was full of wisdom about the human condition of people with disabilities and the often inappropriate, disrespectful and even abusive treatment they received from the people and agencies that were supposed to serve them.

I remember Herb's first presentation at another conference. He was overwhelmed by the idea of having a whole half an hour to speak. How could he possibly fill half an hour? Those of you who knew Herb and/or heard him speak know that half a day, let alone half a hour was nothing.

His second book was called *Learning to Listen*. "Listening" was the operative word for Herb. He was a listener, especially to people with disabilities and even more to those incarcerated in institutions. He usually engaged his audience in a dialogue, extending their awareness of what they heard and saw and of what they instinctively knew. He often did this with wit, occasionally cutting, but always illuminating and always leading people to seek the achievement of inclusive communities. He spoke of people "accused of having autism," and with that phrase painted a painful picture of the life experiences of individuals with autism and their families. Another favorite of mine was Herb's substitution of the word "freedom fighters" for those individuals typically known by program staff as "runners."

Herb was our freedom fighter. When parents and advocates went to the Massachusetts State House trying to pass legislation to prohibit the extreme, painful, and sometimes gruesome practices professionally inflicted upon people with autism, Herb was there. Although there were few professionals to support this fight, Herb was constantly with us. Advocacy was an essential part of his life. As a professional, he was not above spending an evening, a Sunday or even the entire weekend developing, copying and collating papers to make our case to the legislature to end the abuse and violence. He was our friend, and a professional of great courage and conviction.

When a group of individuals was forming an organization with standards of social justice to protect people with autism and similar disabilities, Herb did not hesitate to help form the incorporation for the Autism National Committee. He blithely accepted its first presidency because we had clear standards for membership, information and advocacy, and a commitment to greater understanding (as did Herb). Here was yet another opportunity to speak out and educate all the players — the individuals themselves, their families, and the providers of education and human services.

I was blessed many times in my friendship with Herb, most of all through his special and close relationship with my son, Robert. Herb talked about his favorite image of Rob which was in Herb's kitchen, drinking champagne from a fluted glass on St. Patrick's Day. Not the usual image of people "accused of having autism," but as Herb would say, "Why shouldn't he be drinking champagne like the rest of us?" Herb made community happen.

At Herb's memorial service last April, Rob, said, "I want everyone to know Herb loved everyone. He is now an angel in God's army" and, (reminding us that Herb was also a composer of music and a poet) "Herb is going to many operas in heaven. His days are spent reading poetry and his nights are filled with music."

We must accept Herb's challenge and strive to keep Herb's memory, words and works alive. We have lost a great teacher and a passionate and loving friend. We are all richer, more sensitive and more committed to the struggle for social justice for everyone just by having known Herb.

Come, my friends,
'Tis not too late to seek a newer world…
One equal temper of heroic hearts
Made weak by time and fate, but strong in will
To strive, to seek, to find, and not to yield.
— Tennyson

And we shall miss him.

Given by Barbara Cutler at the Autism National Committee Conference,"The Human Touch," October 1998.

Remembering Herb

BY ROBERT CUTLER

I am sad. The world lost a good man. Herb is still part of my circle in spirit form. He went to heaven and is safe.

I will type about Herb Lovett and how his work will continue. I am writing this for everyone to hear. What was Herb to me? The answer lies in my heart and soul. Last December at TASH, I typed that Herb would take Gunnar's place. What I did not realize was Herb would be in heaven helping the people who died needlessly in institutions.

I want everyone to know Herb loved everyone. He is now an angel in God's army. His job is to help in deciding which behaviorist gets into heaven or ends up in hell. Herb is going to many operas in heaven. His days are spent reading poetry and his nights are filled with music.

Herb wants Michael to build a memorial for the thousands of people who are in institutions.

I will help in freeing everyone from places that use aversive treatments. I will stand and fight against all odds. We need to rally everyone. It is time to fight like the battle of the bulge. It is time to start a revolution and I am ready.

The whole world, Anne, Pat, Sue, everyone in the world of autism. Doug Biklen, Temple Grandin, William Christopher. Time to begin.

I also want to tell people life is hard, but we [must] never stop trying. Fortunately, I have family and friends who support me in my goals for a safer life for all.

Michael, I hope will meet with me so I can type and tell him something. Michael can be on my panel, too. He will replace Herb in a way the world cannot understand, but I do. I hope Michael realizes one of the reasons for Herb's success was because of Michael.

When I typed, God said it was okay that Herb loved Michael. God wants love in His world, not hatred. I understand this from observing. Behaviorists observe us, but we observe, too.

Herb's life needs to live in our hearts and souls. Here, today, we [should] all take a stand that no longer will suffering be allowed. No more, no more!

DIRECTOR OF MENTAL RETARDATION/DEVELOPMENTAL DISABILITY SERVICES

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WHAT'S WRONG WITH THE FEDS?

MARK A. MLAWER

In 1975, Congress passed the statute now known as the Individuals with Disabilities Education Act (IDEA). The IDEA grants students with disabilities the right to a free, appropriate public education in the least restrictive environment (LRE).

However, the LRE requirements are often ignored. This is clear from federal monitoring data, and also the obvious conclusion from large state variations in placement rates. Because the U.S. Department of Education (DOE) briefly focused on the latter issue almost a decade ago — only to drop it unceremoniously rather than act on it — it behooves the national inclusion community to reassess the arguments DOE offered in light of the current data.

The IDEA assigns the responsibility of ensuring that school districts comply with it to state educational agencies (SEAs). DOE has the obligation of making certain that SEAs fulfill their oversight, compliance, and enforcement responsibilities. **If DOE does not adequately fulfill its obligation it is less likely that SEAs will fulfill theirs, and if SEAs do not live up to their responsibilities it is less likely that school districts will fully implement the IDEA.**

Unfortunately, school districts are not fully implementing the IDEA. While little research has been done on the extent of special education noncompliance nationwide, one study broke down DOE state monitoring data, collected from April 1989 to February 1992, to the school district level and discovered high levels of noncompliance:[1]

Requirement	Districts Monitored	Districts in Noncompliance	Percentage in Noncompliance
IEP	165	150	90.9%
LRE	165	143	86.7%
Procedural Safeguards	165	152	92.1%

In light of widespread school district noncompliance, one must conclude that SEAs are not living up to their responsibilities. It follows that DOE has not been successful at ensuring that SEAs fulfill their obligations.

Has DOE made a good faith effort to ensure that SEAs live up to their responsibilities? With the exception of several highly publicized and unique situations, DOE appears never to take meaningful enforcement steps against states exhibiting continuing noncompliance. This is fatal to IDEA compliance because "[c]reating new arrangements is precisely the injunction of the act. If the act is respected, executive and judicial enforcement will often be necessary."[2] It is difficult to imagine full implementation of any law requiring social change in such a lax enforcement atmosphere, and we ought not be surprised at the results.

One result, given DOE's and SEAs' abdication of their responsibilities, is that the burden of achieving compliance at the school district level is on the shoulders of parents. For example, parents often must go through the expense and emotional pain of due process hearings to attempt to achieve inclusive placements in their neighborhood schools. Executive enforcement of the LRE requirements would prevent the need for many of these hearings, and level the playing field between parents and school districts considerably.

The tables on page 27 set forth the most recent federal data on placement rates of students in segregated school and self-contained classroom settings. **Clearly, where a student lives has a strong influence on the restrictiveness of his or her educational placement. Even within states, comparisons between school districts often lead to the same conclusion.**[3]

A recent comparison of two neighboring districts provides a telling example. The two districts are Massapequa and Seaford, New York, which are "in many ways indistinguishable." But

> [i]f Caitlin had lived in Seaford, administrators never would have balked at removing her from isolated special education classes, and if Michelle had lived in Massapequa, she couldn't have gotten out of them. ...The girls' stories ... dramatize how the personal philosophies of the special education directors in Long Island's 125 districts can produce diametrically different educational programs."[4]

That "personal philosophies" and other factors have more influence on placements than the LRE requirements is precisely the conclusion DOE has run away from in recent years.

Given the large number of students served nationwide, it is illogical to conclude that differences in the populations and needs of students can explain the variation in placement rates across states. DOE itself reached this conclusion in 1989:

> It is reasonable to assume that the needs of students are broadly similar across States, and that random variation would be rather small in the summary data on the large number of students served by a State. Thus, the extent of variability suggests that *factors in addition to the characteristics of students determine educational placements, and that the decision-making power vested in the IEP process has not been sufficient to overcome these factors.*[5]

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WHAT'S WRONG WITH THE FEDS?

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By 1992 advocates had reason to feel nostalgic for the honesty and clear reasoning of the 1989 report. After noting in the 1992 report that placement rates "vary considerably" across states, DOE wrote:

> This State variability is likely due to a number of factors including actual differences in the populations and needs of students, the roles of private schools and separate facilities in the State, different State reporting practices and interpretations of Federal data collection forms, and state special education funding formulas."

In light of the monitoring findings cited above, it is curious that an obvious possibility — that LRE violations are a major cause of the variation in placement rates — is not even mentioned by DOE. This omission is especially startling since three of the factors advanced by DOE violate the LRE requirements. **A student cannot be segregated due to the role of private schools and separate facilities, or due to a state's funding formula.** To remove a student from a general education setting, a public agency must show that "education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (20 U.S.C. § 1412 (5) (B)). States in which any of these three factors play a role in placement decisions are violating the LRE requirements.

It is also interesting to note that as early as 1982 DOE urged states to review "all State policies and procedures to determine whether they facilitate or inhibit the implementation of the LRE mandate at the local level...." Apparently this effort was unsuccessful.

As to DOE's attempt to ascribe some of the state variation in placement rates to actual differences in student populations and needs, one can only remind the agency of its 1989 reasoning: it would be quite remarkable if, with such a large number of students served nationwide, differences in individual needs accounted for the variation. DOE did not advance any reasons in 1992 for its quiet rejection of its 1989 conclusions and, of course, inadvertently confirmed those conclusions by reciting the three factors that violate the IDEA.

DOE's apparent belief that the public has significant memory lapses regarding its pronouncements reaches its zenith with its 1992 claim that data reporting problems account for some of the state variation in placements. In 1991 DOE claimed to be working with states to resolve these problems." However, DOE had been making this claim for some time. In 1982 it noted a significant increase during the previous year in the use of self-contained settings, an increase "primarily attributable to ten states." These states reported that several factors were involved "including clerical or reporting errors"; DOE asserted that it would "examine these factors during the coming year with the goal of providing technical assistance to SEAs as needed" (*Fourth Annual Report*, p. 5). In 1989 DOE claimed that it had "worked extensively with States during the past two years to improve the comparability of data" (*Eleventh Annual Report*, pp. 29-30). In 1990 DOE wrote of its intentions to

> provide individualized technical assistance to reduce the incidence of misinterpretation of instructions; clarify reporting instructions by defining terms more precisely; distribute and update a data dictionary to include terms that are subject to alternative interpretations; and develop decision rules that cover a wider range of possible student placement patterns."

But DOE, prior to 1991, did not regard reporting errors as a major factor impacting state variation in placement rates. In fact, in 1989 DOE concluded that "...it is not likely that procedural or terminology differences could account for the variance reported here" (*Eleventh Annual Report*, pp. 29-30). In 1990 DOE stated:

> State variation in reporting practices does not in itself account for the extent to which differences in placements exist among States. It appears that, in addition to variation caused by reporting practices, there remain *significant* State-to-State differences in the actual use of the various placement options. (*Twelfth Annual Report*, p. 29, emphasis added)

While one might wonder whether an agency that admittedly does not ensure comparability of data is able or willing to ensure compliance with the IDEA's substantive requirements, it should be noted that DOE has recently asserted that state data collection and reporting have improved.[10] Of course, data problems might still be trotted out by DOE as an explanation of state variation in placement rates, but the issue is not even mentioned in its recent reports.[11] To discuss it fully and honestly would start a chain of reasoning which would lead directly to the necessity of applying meaningful sanctions to SEAs which do not ensure compliance with the LRE requirements. This is a step that DOE on its own does not seem likely to take.

The most plausible explanation for state variation in placement rates remains noncompliance with the LRE requirements, noncompliance that DOE has amply documented through its monitoring process but done little to stop.

In light of the extent and longstanding nature of noncompliance nationwide, it is surprising to discover that DOE regards itself as having a "strong accountability system" in relation to states (*Nineteenth Annual Report*, p. III-45), and monitoring procedures that "*ensure* compliance" (*Eighteenth Annual Report*, p. 113; *Nineteenth Annual Report*, p. III-48, emphasis added). Indeed, DOE's reports often simply assert conclusions, rather than offering evidence and arguments for those conclusions:

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> The environments in which students receive services *vary according to the needs of the child. For example*, in 1994-95, 87 percent of students with speech and language impairments were served in regular classes for 80 percent of the day or more, as compared with 9.7 percent of students with mental retardation. (*Nineteenth Annual Report* , p. viii; emphasis added; see also p. III-2)

Less than 10% of students with mental retardation being served in regular classes certainly does not support DOE's fanciful 1997 notion that placements vary according to the individual needs of students.

Finally, DOE's recent reports to the public also contain internal inconsistencies. For example, in its 1996 report DOE asserts that regular classroom placements have increased, resource room placements have decreased, and "[o]ther placement percentages have remained stable" (*Eighteenth Annual Report*, p. 66; see also p. xix). But when DOE attempts to justify its decision *not* to focus its LRE monitoring on students who are completely segregated from their nondisabled peers, it claims that this "reflects a decrease nationally in separate school placements" (p. 111). Have these placements remained stable or decreased? The answer appears to depend upon which chapter of DOE's report one is reading, and the agenda being advanced therein.

The national inclusion advocacy community must develop and implement strategies which insist that DOE finally does its job. In spite of its behavior, DOE's customers are not SEAs, its customers are students with disabilities and their families. DOE's decision not to focus its LRE monitoring on segregated students must be vigorously opposed in light of the placements still imposed on many students with significant disabilities. **DOE must tell Congress and the American people the truth even when the truth indicts its own performance, and must set forth a meaningful plan to end — after twenty years — LRE noncompliance nationwide.** Similarly, advocates who work on the policy and systemic aspects of issues related to LRE compliance must examine ourselves: to the extent that our strategies have not worked, we must go back to the drawing board. It may well be time to use more aggressive tactics.

Mark A. Mlawer was Executive Director of the Maryland Coalition for Inclusive Education from 1988-1995, and represented 18,000 students with disabilities on the Management Oversight Team of the Baltimore City Public Schools from 1994-97 pursuant to federal court order. He is currently a consultant.

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[1] National Council on Disability, *Serving the Nation's Students with Disabilities: Progress and Prospects* (Washington, D.C.: National Council on Disability, 1993), pp. 3-4, 6.

[2] Thomas K. Gilhool, "The Right to an Effective Education: From *Brown* to PL 94-142 and Beyond," in *Beyond Separate Education: Quality Education for All*, ed. Dorothy Kerzner Lipsky and Alan Gartner (Baltimore: Paul H. Brookes, 1989), p. 246. Another writer argues that the success of racial desegregation did not depend on participants' support for principles of equality: "Rather, the single most important factor is very often the willingness and ability of authorities to apply enforcement mechanisms that ensure participants' compliance with the desegregation mandate." Robert C. Serow, *Schooling for Social Diversity: An Analysis of Policy and Practice* (New York: Teachers College Press, 1983), p. 45.

[3] For one example see the district-by-district statistics in "Special Education on Long Island: Anatomy of the System," *Newsday*, November 16, 1997, pp. J4-24.

[4] Jack Sirica, "Close, Yet So Far," *Newsday*, November 13, 1997, p. A6.

[5] DOE, *Eleventh Annual Report to Congress on the Implementation of The Education of the Handicapped Act* (Washington, D.C.: DOE, 1989), p. 29; emphasis added.

[6] DOE, *Fourteenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act* (Washington, D.C.: DOE, 1992), pp. 22-24.

[7] DOE, *Fourth Annual Report to Congress on the Implementation of Public Law 94-142: The Education for All Handicapped Children Act* (Washington, D.C.: DOE, 1982), p. 33.

[8] DOE, *Thirteenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act* (Washington, D.C.: DOE, 1991), p. 29.

[9] DOE, *Twelfth Annual Report to Congress on the Implementation of The Education of the Handicapped Act* (Washington, D.C.: DOE, 1990), p. 29.

[10] DOE, *Seventeenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act* (Washington, D.C.: DOE, 1995), pp. xx, 14; *Eighteenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act* (Washington, D.C.: DOE, 1996), p. 66; *Nineteenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act* (Washington, D.C.: DOE, 1997), p. III-3.

[11] One recent cursory mention was found: after asserting that progress has been made in educating students in regular classes, schools, and resource rooms, DOE notes that this progress has been "somewhat inconsistent across ... States," *Nineteenth Annual Report* , p. III-5.

TABLE 1:

Data are for students ages 6-21, 1994-95 school year. Source: U.S. Department of Education, *Nineteenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act,* 1997, p. A-50.

STATE	SEGREGATED SCHOOL (%)	STATE	SELF-CONTAINED CLASS (%)
New York	9.52	Louisiana	42.41
New Jersey	8.05	New Mexico	35.23
Illinois	5.89	New York	34.89
Maryland	5.67	Florida	31.96
Massachusetts	4.94	Illinois	30
Delaware	4.3	New Jersey	27.82
Michigan	4.25	Pennsylvania	27.35
Minnesota	4.13	Maryland	26.23
Connecticut	3.97	Mississippi	26.21
New Hampshire	3.91	Georgia	26.11
Pennsylvania	3.43	South Carolina	25.53
Rhode Island	3.13	Virginia	25.42
Nevada	3.01	Indiana	24.1
California	2.85	Rhode Island	23.92
Utah	2.77	California	23.87
Nebraska	2.55	Texas	22.76
Florida	2.51	Michigan	21.22
Arizona	2.42	Utah	20.04
Missouri	2.13	Hawaii	19.63
Oregon	1.99	Missouri	19.18
Kansas	1.8	Arizona	18.87
Iowa	1.79	Wisconsin	18.67
Ohio	1.75	New Hampshire	18.33
Vermont	1.73	Tennessee	17.85
Tennessee	1.67	West Virginia	17.72
Virginia	1.53	North Carolina	17.49
Colorado	1.49	Connecticut	17.43
North Carolina	1.48	Alabama	16.27
South Dakota	1.42	Kansas	16.13
South Carolina	1.41	Washington	15.04
Alabama	1.39	Massachusetts	14.88
Maine	1.34	Kentucky	14.71
Indiana	1.33	Oklahoma	14.4
Louisiana	1.26	Arkansas	13.87
Arkansas	1.2	Ohio	13.51
Wisconsin	1.2	Nevada	12.3
Wyoming	0.81	Nebraska	11.58
Montana	0.74	Maine	11.31
North Dakota	0.72	Alaska	11.17
Oklahoma	0.71	Montana	10.33
Washington	0.64	Colorado	8.52
Georgia	0.62	Iowa	8.42
Kentucky	0.6	Wyoming	8.29
Mississippi	0.57	Idaho	7.61
Texas	0.54	Oregon	7.33
Idaho	0.53	Minnesota	7.18
West Virginia	0.51	Delaware	6.7
Hawaii	0.4	North Dakota	6.69
Alaska	0.1	South Dakota	6.34
New Mexico	0.04	Vermont	3.43

TABLE 2:

Data are for students with mental retardation ages 6-21, 1994-95 school year. Source: U.S. Department of Education, *Nineteenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act,* 1997, p. A-56.

STATE	SEGREGATED SCHOOL (%)	STATE	SELF-CONTAINED CLASS (%)
New Jersey	31.91	Louisiana	82.54
New York	30.76	New Mexico	80.41
Maryland	18.02	Florida	80.18
Illinois	16.16	Texas	79.88
Nevada	14.7	Illinois	76.25
Michigan	13.44	Rhode Island	75.95
Delaware	13.4	Utah	74.22
Rhode Island	12.03	California	72.71
Missouri	11.78	Indiana	72.53
Florida	11.38	Virginia	70.76
California	9.87	Arizona	68.65
New Hampshire	9.52	Missouri	66.23
Minnesota	7.98	Georgia	65.95
Connecticut	7.57	Connecticut	65.27
Utah	6.97	Mississippi	64.93
Pennsylvania	5.94	Maryland	63.2
Arizona	5.84	Pennsylvania	62.35
Massachusetts	5.09	Wisconsin	61.98
North Carolina	4.26	New Jersey	61.61
South Carolina	4.2	Kansas	61.04
Louisiana	3.67	South Carolina	60.7
Indiana	3.67	Michigan	58.38
South Dakota	3.1	West Virginia	57.64
Maine	2.81	New York	56.74
Texas	2.8	Tennessee	55.94
Tennessee	2.8	Maine	51.62
Alabama	2.77	Hawaii	51.47
Wisconsin	2.77	Nevada	50
Nebraska	2.68	Alaska	48.86
Iowa	2.62	Massachusetts	48.29
Arkansas	2.59	Oklahoma	47.04
Kansas	2.28	North Carolina	46.85
Wyoming	2.24	Oregon	45.87
Virginia	2.06	Montana	45.58
Vermont	1.89	New Hampshire	44.67
Oregon	1.48	Alabama	42.96
West Virginia	1.24	Washington	41.42
Idaho	1.11	Wyoming	41.12
Mississippi	1.1	Colorado	39.71
Oklahoma	0.89	North Dakota	36.55
Georgia	0.78	Arkansas	34.78
Washington	0.71	Nebraska	33.67
North Dakota	0.71	Idaho	29.98
Colorado	0.56	South Dakota	29.47
Kentucky	0.41	Minnesota	28.69
Ohio	0.39	Kentucky	27.65
Montana	0.37	Ohio	26.8
Hawaii	0.16	Delaware	17.32
Alaska	0.15	Vermont	10.07
New Mexico	0	Iowa	8.45

TABLE 3:

Data are for students with serious emotional disturbance ages 6-21, 1994-95 school year. Source: U.S. Department of Education, *Nineteenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act,* 1997, p. A-58.

STATE	SEGREGATED SCHOOL (%)	STATE	SELF-CONTAINED CLASS (%)
California	37.26	Louisiana	67.96
Massachusetts	34.95	Mississippi	57.74
New Jersey	34.05	Florida	56.97
New York	27.76	New Mexico	53.83
Illinois	27.65	Oklahoma	50.2
Maryland	23.79	Indiana	48.64
Ohio	23.78	Kentucky	43.4
Oregon	16.86	Virginia	43.04
Delaware	15.89	Texas	41.96
Arizona	15.19	South Carolina	41.71
Pennsylvania	15	Alaska	40.05
Minnesota	13.02	Illinois	39.61
Tennessee	12.75	Pennsylvania	39.06
Rhode Island	12.26	Missouri	38.83
Connecticut	11.38	New York	38.27
Idaho	10.1	Arizona	38.11
Montana	10.07	North Carolina	38
Michigan	8.28	Maryland	37.95
Virginia	8.08	Arkansas	36.6
South Dakota	7.66	Rhode Island	36.15
Iowa	7.02	California	36.03
Florida	6.84	New Jersey	34.81
New Hampshire	6.71	Hawaii	34.13
Kansas	6.37	Massachusetts	31.33
Louisiana	6.36	West Virginia	30.96
Colorado	6.2	Michigan	30.48
Vermont	6.06	Tennessee	30.09
Missouri	5.1	Nebraska	29.86
Washington	5.09	Georgia	29.46
Maine	4.96	Nevada	29.15
Arkansas	4.9	Wyoming	28.45
Kentucky	4.87	Wisconsin	28
Nebraska	4.85	Utah	27.96
Oklahoma	4.66	Montana	27.39
South Carolina	4.53	Connecticut	26.91
Indiana	4.18	Kansas	26.57
Utah	4.15	Ohio	26.09
Wyoming	4.01	Washington	23.92
North Carolina	3.43	Idaho	19.18
Wisconsin	3.4	South Dakota	18.73
Nevada	3.37	New Hampshire	18.55
Texas	2.08	Oregon	18.06
Georgia	2.04	Alabama	17.9
Alabama	1.97	Maine	17.54
West Virginia	1.28	Colorado	15.95
North Dakota	0.98	North Dakota	14.4
Mississippi	0.38	Minnesota	10.79
Hawaii	0.28	Delaware	8.7
New Mexico	0.12	Iowa	7.65
Alaska	0	Vermont	5.67

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TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information:

( ) Mastercard ( ) Visa ( ) Discover

Card Number____________________

Expiration Date____________________

Signature____________________

( ) I would like to spread my payments out. Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

If you are applying for a student membership, please provide the following information:

Department____________________

College/University____________________

Student I.D. Number____________________

Anticipated year of completion____________________

( ) Include an additional $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone:410/828-8274 Fax: 410/828-6706

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Please notify TASH
of your new address.

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Address Correction Requested

BEST COPY AVAILABLE

NOVEMBER/DECEMBER 1998